FACTORS AFFECTING TREATMENT DECISION MAKING FOR WOMEN WITH BREAST CANCER

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ABSTRACT

This study examined the factors affecting treatment decision making for young women with early stage breast cancer. Thirty women, aged 35 to 52 years, were presented information about two equally effective chemotherapy treatments following surgery for breast cancer using an educational instrument called a "decision board." Although equally effective, the treatments differ with regards to side effects and treatment schedule. The purpose of this research was to investigate what factors affect the decision-making process. Following administration of the decision board, women were given a take-home version to review and asked to return one to two weeks later with a decision, at which time they completed a questionnaire. The theoretical framework for this study was constructed from the literature on self-directed learning and critical thinking.

Overall, the factors rated most important to the treatment decision were related to quality of life, side effects, and length of treatment. Five factors were found to be rated significantly different by the women who chose one treatment versus the other in terms of importance to their decision. These were side effects in general, vomiting, hair loss, family role, and the number of trips to the cancer centre required for treatment.

Implications and recommendations for patient education, research, and practice evolved from the findings of this study.

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CHAPTER ONE: THE PROBLEM

Introduction

Traditionally, patients have relied on their physicians for advice regarding treatment of illness and disease. However, in recent years a strong concern has been raised by society to ensure that patients, as health care consumers, are fully informed about their prescribed care. In addition, in many areas, research has enabled us to discover new and improved treatments that offer better survival outcomes. In some cases, this has allowed health care professionals to offer more than one treatment option to their clients from which their clients can choose. As a result, patient education and informed decision making have become important components in the provision of health care. In the field of oncology, specifically breast cancer, this is particularly true.

Breast cancer affects one in nine women in Canada (Canadian Cancer Statistics, 1993). This means, if every woman lived to ninety years of age, one woman out of every nine is expected to develop breast cancer at some point during her lifetime and one woman in twenty-three will likely die of this disease. It is the leading cancer affecting women and is probably the cancer most feared by women. Breast cancer is the leading cause of death among women 35 to 55 years of age. It is more prevalent in North America than throughout the world.

This study involved thirty premenopausal women newly diagnosed with Stage II breast cancer seen at the Hamilton Regional Cancer Centre for chemotherapy treatment following surgery. It examined the process of patient participation in treatment decision making.

Background

Breast cancer, upon diagnosis, is classified as Stage I, II, III, or IV, a measurement of the extent of the disease (Scanlon, 1991). Stages I and II are considered early breast cancers and are treatable with a definite chance of cure. Stage I refers to the presence of cancer in the breast only. Stage II refers to the detection of cancer in the breast and in the lymph nodes (glands) in the axilla (underarm area) on the same side of the body. Presently the standard treatment for premenopausal women with Stage II breast cancer is chemotherapy following initial surgery (Harris, Lippman, Veronesi & Willett, 1992).

There are a number of alternative options for the treatment of breast cancer with chemotherapy. Recently a randomized clinical trial revealed that two different regimens of chemotherapy are equally effective in treating premenopausal women with Stage II breast cancer (Fisher, Brown, Dimitrov, Poisson, Redmond, Margolese, Bowman, Wolmark, Wickerham, Kardinal, Shibata, Paterson, Sutherland, Robert, Ager, Levy, Wolter, Wozniak, Fisher, & Deutsch,

1990). For this study patient accrual was conducted from 1984 to 1988 acquiring over two thousand women throughout Canada and the United States. The chemotherapy regimens are adriamycin (doxorubicin) and cyclophosphamide (AC), and cyclophosphamide, methotrexate and fluorouracil (CMF). The two regimens of chemotherapy differ from each other with regards to side effects, treatment schedule, duration of overall treatment, and the number of required clinic visits. However, AC and CMF have been shown to provide the same survival outcome, at six years, with this patient population (NSABP Report, 1993). This information now allows nurses and physicians to present premenopausal women, with Stage II breast cancer, a choice of chemotherapy. Following the chosen treatment regimen, the patients receive the same follow-up care.

The AC regimen is comprised of four cycles of treatment, each one 21 days apart. One cycle of AC involves receiving two drugs consecutively through an intravenous line in the arm. The administration of these two drugs takes approximately 60 minutes. The AC regimen requires four visits for treatment and is usually completed within 63 days. Occasionally treatment is delayed due to low blood counts, other side effects, or an acute illness. If a woman experiences any of these, treatment may be delayed a week to allow her body to recover. To give treatment under these circumstances could worsen the patient's condition.

The CMF regimen involves six cycles of treatment that is repeated every 28 days. One cycle of CMF involves two clinic visits. On Day One a patient receives two drugs, methotrexate and fluorouracil, consecutively through an intravenous line in the arm. This is repeated one week later on Day Eight. The administration of these two drugs takes approximately 20 minutes each time. The third drug, cyclophosphamide, is in tablet form. A woman takes the prescribed number of tablets every morning for 14 days, starting on Day Two of each cycle. The CMF regimen requires twelve clinic visits and is usually completed within 140 days or six months. Again, occasionally a treatment is delayed a week due to low blood counts, other side effects or an acute illness.

Since August 1993, the staff of the Hamilton Regional Cancer Centre have been offering premenopausal women newly diagnosed with Stage II breast cancer this choice. The Hamilton centre is the only centre in Ontario, and in Canada, offering this treatment decision opportunity. (The other centres in Ontario are Thunder Bay, Sudbury, Windsor, London, Toronto, Kingston, and Ottawa.) The other seven centres have continued to offer CMF, as CMF is regarded as the "standard" treatment. The physicians at the Hamilton Regional Cancer Centre felt that given the information about the differences between AC and CMF, women should have the opportunity to make their own decisions regarding their

treatment. The choice a woman makes would likely be based upon her personal circumstances, values and beliefs.

In recent years, a teaching tool has been developed at the Hamilton centre to assist patients in choosing between treatment options. This teaching tool, called a "decision board," acts as a visual aid with written information (Levine, Gafni, Markham, & MacFarlane, 1992). Presently, the Hamilton centre is the only institution using such an instrument; however, several inquiries have been made by other centres. Two decision boards have been designed and are presently in use at the centre. The first board presented "chemotherapy versus no chemotherapy" to Stage I breast cancer patients (Levine et al., 1992) and the second board presented "radiation therapy versus no radiation therapy" to Stage I breast cancer patients (Whelan, 1993). I have developed a decision board to clearly explain the differences between AC and CMF to patients to assist them with their decision. This is the first time a decision board has been used in the setting of Stage II breast cancer. Also, the two previous decision boards have displayed a "treatment versus no treatment" choice. In this study the choice was between two different treatment durations and their associated differing toxicities.

Problem Statement

It was the intent of this research study to develop an understanding of the decision-making experience for premenopausal women newly diagnosed with Stage II breast cancer when choosing between two chemotherapy regimens.

The purpose of this study, the primary objective, was to examine the factors affecting this decision-making process. The secondary objectives included: i) measuring the learning that occurs following presentation of the information, and ii) investigating the quality of life of these women at the time of the decision. These additional data about each subject's learning and quality of life, were intended to help the researcher discover further contributing factors to the decision-making process.

The main research question asked was:

> What factors affected the decision-making process for women newly diagnosed with Stage II breast cancer when choosing between two equally effective chemotherapy regimens?

The following sub-questions were also asked:

i) What and how much learning occurred when the decision board was used to convey the information about each regimen?

ii) Were there significant differences in the "quality of life" experienced by the women who chose one chemotherapy regimen or the other?

iii) Were there significant demographic differences between the women who chose one chemotherapy regimen or the other?

iv) Was there a significant difference between the number of women who chose one chemotherapy regimen or the other?

Rationale

The concept of giving patients a choice between two chemotherapy regimens to treat a cancer is relatively under-researched in oncology. Research has proven that the survival outcome of the two treatments is the same at six years (NSABP Report, 1993). As a health care provider, it was important to investigate why women, when presented the facts, chose one course of treatment over another.

What factors were most important to women with breast cancer at the time of the treatment choice? Was it the side effects? Was it their personal situation at home? Was it the distance they had to travel for treatment? Was it their work schedule or finances? Was it their previous experience with another cancer patient? Did the method of presentation, the decision board, affect their decision? Was the decision a difficult one to make? Were they pleased

to be involved in choosing their treatment or did the decision cause more anxiety?

It was anticipated that the answers to these questions would tell us what issues were of foremost concern for this population. This included whether this opportunity for patient involvement in treatment decision making was worthwhile, or whether there is something that can be changed to make treatment easier for women to cope with such as improved symptom control or psychosocial support. The results may indicate that one regimen was strongly preferred over the other. Knowing the reasons behind these patients' decisions may help the health care team at the Hamilton Regional Cancer Centre to better understand the physical, psychosocial and informational needs of young women with early stage breast cancer. It was hoped that these results would help lead to the formulation of recommendations for the future implementation of strategies and interventions.

Theoretical Framework

The theoretical framework for this thesis lies within the realm of adult education. The link to adult education is evident in two ways. First, there has been a general shift occurring within the health care system towards increased patient awareness and self-managed care. Second and more importantly, within the area of oncology and particularly breast cancer, a greater emphasis has been

placed on quality of life issues as defined by the individual patient. As a result, adult education has an important role to play to increase patient understanding and participation in their own care. The work of Malcolm Knowles, Philip Candy, and Stephen Brookfield were used to support this research.

Following Knowles' work, many adult learning principles were practised during this study. The patients came by choice to the centre to seek out more information and a specialist's opinion regarding treatment. They were motivated to learn about treatment alternatives to increase their chance of survival or improve their quality of life. They were treated with respect for their opinions and previous knowledge and experience. Each individual was allowed to choose the treatment she saw as best for herself, given her uniqueness and individual needs. The presentation of the decision board was geared to the pace of the learner and time was allowed for questions and comments. These learning principles are the basis for Knowles' model of andragogy. The term andragogy refers to "the art and science of helping adults learn" (Knowles, 1990, p. 54).

Philip Candy (1991) described self-directed learning as both a process (method of learning) and a product (learner characteristic). This means it is not simply a single phenomenon. He saw self-directed learning as having four dimensions: personal autonomy, self-management, learner-

control, and autodidaxy. Personal autonomy refers to self-direction as a personal quality or attribute. Self-management refers to the ability to conduct one's own learning and education. Learner-control refers to the learner, within a formal educational setting, being responsible for the content, method, pace, sequence, and evaluation of the learning outcome, for example. Autodidaxy refers to the individual pursuit of learning opportunities other than in an institution. The focus throughout this thesis was on two of these dimensions, personal autonomy and autodidaxy.

Stephen Brookfield (1987) has written about critical thinking and decision making. He described components of the critical thinking process, characteristics of critical thinkers, the importance of critical thinking for individual development and ways to encourage others to think critically. Most adults function as critical thinkers to some extent but the degree can vary dramatically from person to person. According to Brookfield, making judgments, choices, and decisions are examples of critical thinking. His work was used to support this research since patients were presented with the opportunity to think critically about treatment options.

It is important to note that expected utility theory was investigated for its support and use with this research. The literature contained evidence to disprove its strength

and reliability when looking at attitudes towards risk or chance (Tversky & Kahneman, 1981) and in particular when studying patients with a life-threatening illness (Siminoff & Fetting, 1989). In place of the expected utility model, Tversky and Kahneman suggest a descriptive model called prospect theory. However, both expected utility theory and prospect theory were designed to predict choice and, since that was not the purpose of this study, neither were used for theoretical support.

Definitions

Chemotherapy

Chemotherapy is the broad term for the classification of cancer-fighting drugs. There are approximately thirty different drugs that fall into this category. Different individual drugs and different combinations of drugs are used to treat the many forms of cancer according to the area of the body affected. Chemotherapy is most often available as an injectable solution, usually given intravenously, but is also available in tablet form.

Decision Board

The decision board is a visual aid designed to assist health care professionals to inform and teach the patient population about treatment options. The boards so far have been made of foam core and use bar graphs or pie

graphs/wheels and written material to communicate information. Presentation of the decision board is a building process. Cards containing the information are read aloud and then attached with velcro to the board in a particular sequence.

Health Care Professional

A health care professional refers to a nurse, physician, social worker, dietician or other professional disciplines that act as caregivers and members of the health care team.

Medical Oncologist

This term refers to a physician who has specialized in the treatment of cancer with medication such as chemotherapy or hormonal therapy.

Patient

This term refers to the person receiving health care. In this study the sample patients were premenopausal women newly diagnosed with Stage II breast cancer.

Premenopausal

This term refers to the reproductive status of a woman prior to experiencing menopause.

Researcher

In this study the researcher was a registered nurse employed as an Oncology Nursing Fellow in breast cancer at the Hamilton Regional Cancer Centre. This fellowship, and consequently this study, was funded by The Canadian Breast Cancer Foundation.

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter begins with a review of the literature pertaining to the theoretical framework of adult education. This is followed by a summary of the research conducted in the area of patient decision making, related to oncology patients, and then a synopsis of the work that has been done to develop and implement the decision board concept.

Andragogy and Self-Directed Learning

The purpose of this section is to review the theoretical foundations of adult education specifically andragogy, self-directed learning, and critical thinking. Self-directed learning is a goal of andragogy and both include components of critical thinking.

Malcolm Knowles (1975, 1980, 1984 & Associates, 1989, 1990) is credited with having had the strongest influence on adult education since the mid 1970s. He introduced the European concept of andragogy to North America in 1968. Andragogy had been defined by European adult educators as "the art and science of helping adults learn" (Knowles, 1990, p. 54). Originally, Knowles wrote about andragogy and pedagogy as a dichotomy, defining pedagogy as "the art and science of teaching children" (Knowles, 1990, p. 54). However, he later revised his interpretation to view the two concepts as along the same continuum but at opposite ends.

Pedagogy refers to the traditional teaching model where learning is teacher-directed and the learner is dependent upon the teacher. Other assumptions that characterize pedagogy are: The teacher is responsible for deciding what and how a subject is to be learned; the teacher's, not the learner's experience is valued; learners are told what and when they must learn; learning is subject-centred; and learner motivation comes from external pressures (Knowles, 1990).

At the other end of the education continuum is the model of andragogy or learning that is learner-directed. The role of the teacher or facilitator within this model is to help the learner take increasing responsibility for her own learning to become self-directed.

Andragogy is described by Knowles as a model of basic assumptions rather than a learning theory. It is most often used to refer to adult learners, but not exclusively. The basic assumptions of andragogy are summarized below (Knowles, 1990):

The need to know. "Adults need to know why they need to learn something before undertaking to learn it" (p. 57). Once learners recognize the value of the new knowledge and how they can apply it, they are more likely to proceed with the learning endeavour. Therefore, one of the first tasks of a facilitator should be to help the learners become aware of their need to know.

The learner's self-concept. "Adults have a self-concept of being responsible for their own decisions" (Knowles, 1990, p. 58). They also have a deep psychological need to be recognized by others as being capable of self-direction, as well as taking care of themselves and their interests. Feelings of resistance or resentment may surface when an adult learner feels the beliefs or demands of others are being imposed. Frustrating situations can arise when adult learners, who are otherwise self-directing, present themselves in an educational setting and want to be taught, in a traditional sense, but at the same time expect to be treated as responsible and independent. Educators are responsible for providing a supportive environment and creating learning experiences to encourage the learner to move from dependency to self-directedness.

Knowles (1980) identified five implications for practice that support the learner's self-concept: the learning climate; diagnosis of needs; the planning process; conducting learning experiences; and evaluation of learning. The physical and psychological learning climate should make adults feel at ease, respected, and supported. The diagnosis of needs emphasizes involving learners in the self-diagnosis of their learning needs. An ideal model of performance is constructed to which the learners compare their present level of competency, measure the existing gaps and identify learning needs. The process of planning

learning must involve the learner, with the educator acting as a guide and content resource. Conducting learning experiences is the mutual responsibility of the learner and teacher. The teacher's role is defined as a facilitator, resource person, and catalyst more than an instructor. The emphasis in this learning process is on self-evaluation with the teacher assisting the learner with gathering evidence regarding progress towards fulfilling learning needs.

The role of the learner's experience. "Adults enter into an educational activity with both a greater volume and a different quality of experience from youths" (Knowles, 1990, p. 59). In any group of adults there will be a wide range of individual differences which require an emphasis on individualization of teaching and learning strategies. Also, an adult learner's self-identity is defined based upon experience. This makes it especially important to accept and value the learner's previous experience, otherwise self-identity may be threatened.

Knowles (1980) identified three implications for practice related to the learner's experience. The first is to emphasize experiential learning techniques that acknowledge the experience of adult learners such as group discussion, role playing, seminars, and field projects. The second is to emphasize the practical application of new learning: that is, how learners can apply new knowledge to their every day lives. The third is unfreezing and learning

to learn from experience. Activities should be designed to encourage adults to look at themselves more objectively and to examine their preconceptions and open their minds to new approaches.

Readiness to learn. "Adults become ready to learn those things they need to know and be able to do in order to cope effectively with their real-life situations" (Knowles, 1990, p. 60). Readiness to learn must be assessed on an individual basis. A prime source for readiness in learning is the developmental tasks one encounters at all developmental stages. Although it may occur naturally, this readiness to learn can be encouraged in the learner. Often it may be important for the facilitator to consider the developmental stage of the learner in an attempt to coordinate the timing of developmental tasks with appropriate learning experiences. Consideration of developmental tasks is also helpful when trying to form groups of learners to ensure a common readiness and interest is present (Knowles, 1980).

Orientation to learning. Adults are life-centred, task-centred or problem-centred rather than subject-centred (Knowles, 1990). Adults learn so that they can perform a task better, solve a problem or live in a more satisfying way. Adults are motivated to devote energy to learn something to the extent that they perceive that it will help them to cope with real-life situations. The emphasis is on

the notion that learning experiences should be organized around life situations rather than according to subject areas. Adults are more likely to learn new knowledge effectively when it is presented in the context of application to real-life situations.

Knowles (1980) identified three implications for practice related to orientation to learning. First, the orientation of adult educators must be in tune with the existential concerns of adults so that they are able to develop relevant learning experiences. Second, the organization of the curriculum should follow a sequence that relates to problem areas, not subjects. Third is the design of learning experiences. The problem-centred approach stresses that the starting point for every learning experience is the problems or concerns that adults have as they enter a situation. The problems identified by the facilitator or institution should also be made known so that negotiation between the learner and facilitator can occur.

Motivation. While adults may respond to external motivators such as job title or money, they are more responsive to internal motivators, such as job satisfaction, self-esteem and quality of life (Knowles, 1990). Adults are more motivated to learn when they see self-improvement as the ultimate goal.

Knowles recognized that a learner will move along the continuum towards andragogy at her own individual pace and

that different individuals may be at different places along the continuum. This transition or movement is associated with both the developmental stage of the learner and the attitude of the educator (Knowles, 1975). A primary school teacher can practise methods based upon andragogical assumptions just as a university professor can practise methods based upon pedagogical assumptions. It is hoped that learners within our educational system are exposed to and encouraged towards following andragogy by the time they reach the post-secondary level if not sooner. Similarly, within the health care system there can be a wide range of teaching methods and strategies used by health care professionals to facilitate patient education.

In following the andragogical model, an educator needs to concentrate on the learning process more so than the actual subject area (Knowles et al., 1984). He found the following elements to be necessary for the practice of andragogy:

1) Establishing a physical and psychological climate conducive to learning is very important. The physical environment should be comfortable and conducive to communication among the learners. The psychological environment should include an atmosphere of mutual respect, trust, collaboration, support, pleasure, openness and authenticity and humanness.

2) Learners should be involved in mutual planning. A mechanism needs to be in place within the learning environment that allows for this. People tend to feel more committed to a decision when they have participated in making it.

3) Participants should be involved in diagnosing their own needs, formulating their learning objectives, designing a learning plan, and evaluating their learning. Facilitators need to be available to guide and assist learners in carrying out their learning plans. Evaluation includes evaluating the accomplishments of individual learners as well as the quality of the whole program.

Knowles (1975) believed self-directed learning was effective for several reasons. First, "people who take the initiative in learning learn more things" (p. 14) than passive learners. Second, "self-directed learning is more in tune with our natural processes of psychological development" (p. 14). As we grow and add to our experience we develop a need to be independent. Third, some aspects of education have led to increased learner responsibility, thereby increasing the need for support to enable students to cope with this. As a result, the main purpose of education has shifted towards encouraging the development of skills of inquiry rather than simply transmitting knowledge. Learning is a lifelong process since we learn from all our experiences. The ability to learn on one's own has become a

prerequisite for living in a rapidly changing society. Knowles' assumptions have important implications for health care professionals working with adult patients. Disease, procedures and treatments often interfere with personal privacy, self-esteem and individuality. Adults seek information about their health to increase their knowledge and understanding, to enable participation in their own care, to maintain control, and to maximize their quality of life. Health care professionals should consider the principles of andragogy when educating patients.

Philip Candy (1991) provided a comprehensive and thorough discussion of self-directed learning in his book Self-Direction for Lifelong Learning. Candy emphasized that self-directed learning can be interpreted in two different ways, as a goal of education and as a method of learning. Each of these interpretations is comprised of two distinct dimensions. As a goal or outcome of education, self-directed learning is subdivided into the domains, personal autonomy and self-management. As a method or learning process, self-directed learning is subdivided into the domains autodidaxy and learner-control. These four areas are defined by Candy as the four distinct but related phenomena of self-directed learning. Discussion will centre around personal autonomy and autodidaxy.

Personal autonomy, when referred to with regards to self-direction, has two meanings (Candy, 1991). The first

is the broad definition of "thinking and acting autonomously in all situations" (p. 101) also referred to by Candy as self-determination. The second is what Candy referred to as self-management, meaning "to exert control over one's learning endeavours" (p.101). Therefore, in this paper, the use of personal autonomy or self-determination refers to the first definition while the term self-management is used to refer to the second meaning.

The personal autonomy of an individual may be judged based upon the extent to which he or she conceives goals and plans and formulates independent intentions, exercises freedom of choice in thought and action, uses rational reflection and is able to judge what is morally right with objectivity and relevant evidence, has will power to follow through with plans of action without having to depend on others for reassurance, exercises self-restraint and self-discipline in emotional or challenging situations, and views himself or herself as autonomous (Candy, 1991). This is to say that one is able to develop a personal agenda of objectives and make independent decisions using a sound rationale. An autonomous person has the strength and endurance to see ideas further develop through to completion without relying on the support of others. Candy acknowledged that this definition represents an ideal profile of an autonomous person and therefore it is likely

that few people are able to achieve autonomy in the strongest sense.

So how does one become autonomous? The ability to become personally autonomous increases with age and can be further developed through learning experiences (Candy, 1991). It is not purely maturational nor is it based upon educational experience alone. The continuing development of personal autonomy is a lifelong pursuit involving both formal and informal aspects of education and all aspects of the individual (Candy, 1991).

Autonomy is not simply a personal quality or characteristic but is the interacting relationship between personal and situational variables (Candy, 1991). One does not just become autonomous, but rather is able to think and act autonomously in certain situations. A person can vary in the degree of autonomy exercised from situation to situation. One can be autonomous in some areas and not others.

Adults are presumed to be self-determining individuals but are not always capable of exercising control over their own learning; however, this ability can be learned (Candy, 1991). Autonomy cannot be detected from behaviour alone but must take into consideration the learner's intentions and understanding.

Freedom for a learner in a learning situation does not guarantee autonomy. One cannot give someone autonomy or

force someone to be autonomous but one can provide the supportive environment necessary for autonomous qualities to grow.

The link between the enhancement of personal autonomy and autonomous methods of learning can create some confusion. Individuals may be exposed to autonomous modes of learning without internalising the values of autonomy and conversely may develop autonomy without the exposure to autonomous methods (Candy, 1991). Personal autonomy is not meant to encourage antisocial behaviour. Autonomy involves co-operation, flexibility and mutual respect from contact with and support from others. Cranton (1992) reinforced that for learning to occur there must be interaction between the learner and the environment.

The development of personal autonomy is supported by society as an educational goal; however, the degree of emphasis placed upon personal autonomy will vary according to the learning situation (Candy, 1991). Since autonomy is a process, rather than a product, it should serve as the goal of lifelong education not only that of adult education.

Autodidaxy refers to the independent pursuit of learning opportunities in natural societal settings (Candy, 1991). This kind of learning has been taking place since the beginning of time and accounts for by far the majority of learning that takes place everywhere in the world. People have always encountered new situations and as a

result have entered into the learning process to gain understanding about an unending number of subjects.

Autodidaxy is learner-centred and requires initiative on behalf of the learner (Candy, 1991). It is not a teaching method or technique of instruction. It involves aspects of teaching such as goal setting, searching for resources, attacking the subject matter, responding to feedback, and evaluation (Candy, 1991). However, autodidaxy is not a set process. It unfolds with time and is therefore an unpredictable process. The impact of random events leads to rethinking and reorganizing plans as the project proceeds.

Autodidactics are usually purposeful, disciplined learners who are alert to learning opportunities in a variety of situations. Autodidaxy is often social and does not infer isolation. Much autodidactic learning occurs within group settings such as local community groups.

Autodidactic learners may make use of a wide variety of resources such as individual experts, written material, media and computer programs (Candy, 1991). Tough (1967) suggested that autodidactics seek assistance for four reasons: unfamiliarity with the area of interest; a lack of knowledge; a need for emotional support and encouragement; and to get help with specific problems or information.

The resource person (assistant) chosen by an autodidactic needs to be flexible to the needs of the

learner, have knowledge of the subject matter, have interest in the welfare of the learner, and be an effective communicator (Candy, 1991). Advantageous communication skills should include listening, empathy, respect, and encouragement of learner self-confidence.

According to Candy, the relationship between an autodidactic and assistant is an area that has not been well researched; however, he explained four potential relationships that may develop between the learner and the assistant. These are the relationships between a mentor and protégé, an advisor and graduate student, a counsellor and client, and a librarian and library user. Within this framework, my role as the researcher and the patient's role as the learner parallel the counsellor-client relationship the most closely of the four.

Criticisms of Andragogy and Self-Directed Learning

Andragogy and self-directed learning have prompted debate and controversy over the past few decades. Adult educators and theorists have tried to further clarify self-directed learning through critical analysis. Some of the constructive criticisms of Brookfield (1985, 1986) and Cranton (1992) are discussed.

Stephen Brookfield is well known for his contributions to the study of adult education and, in particular, self-directed learning. In fact, he has written the most

complete analysis of andragogy and Knowles' work available to date. His work provided the primary criticism of andragogy in this review.

Brookfield (1986) recognized that Knowles correctly described andragogy as a "model of assumptions ... not an empirically based theory of learning" (p. 91). However, the misinterpretation of others in this regard has led to some confusion. "Brookfield does not criticize the work of Knowles himself so much as the use of Knowles' work by others" (Cranton, 1992, p. 15). Brookfield himself incorporated some of Knowles' ideas into his own work, but still suggested that both pedagogy and andragogy need to be critically challenged by educators so that more evidence can be collected.

Brookfield (1986) found that most of the research related to self-directed learning has been conducted with samples of white, male, middle-class, well-educated adults. Therefore, the generalizability of the results are rather limited based upon gender, race, culture and educational level. This leads back to the fact that one of the basic assumptions of andragogy is that learners prefer to be and have a deep psychological need to be self-directing. However, with research limited to a specific population, one cannot be sure how it applies to other cultures and societies. Cranton (1992) also noted this as a criticism. Brookfield (1986) stated that "while self-directedness is a

desirable condition of human existence it is seldom found in any abundance" (p. 95) throughout the world. Therefore, perhaps self-directed learning is more characteristic of middle class North American culture and is not as global a quality as we are led to believe.

It should be mentioned that Knowles (1990) did not claim that all learners are self-directed but rather that they have a need to be and recognized as self-directed. Caution should be taken so as not to assume that everyone in all learning situations wants to be or is capable of being completely self-directed. The degree of self-direction is bound to vary among different individuals depending upon the learning situation. Preference for and ability to participate in self-directed learning may also be affected by the outcome of other characteristics such as developmental stage, psychological type, and learning style (Cranton, 1992). Candy (1991) supported this and Knowles (1989) admitted that there are learning situations where self-directed learning is not recommended as the best approach, such as those involving protection of life.

Brookfield (1985) was also critical that learning and adult education are always portrayed as being enjoyable and rewarding. Rarely is an adult made aware that his/her learning experience may cause feelings of anxiety, ambiguity and self-doubt. It is evident that not all adult learners easily adapt to the self-directed role or, for that matter,

the learner role in general. In particular, self-directed learning can be very distressing for some, even those more experienced with the process.

According to Knowles (1990) there are skills required to be a self-directed learner and, as Cranton (1992) noted, these skills are "not ones which the average adult brings to a learning experience" (p. 50). These skills can be fostered given a conducive learning environment, but we cannot expect learners to always arrive with a previous awareness of them.

One of Brookfield's main complaints about self-directed learning is the role of the educator as only a resource person to help meet the needs of the learner. Brookfield (1985) argued that the educator should be responsible for contributing to the direction of learning and should be involved in the discussion of appropriate curricular choices. Educators are at risk of abdicating their role by allowing learners to solely determine the design and management of their personal course of learning (Brookfield, 1985). In addition, Brookfield pointed out that there is yet to be established a set of criteria for measuring the purpose, success or appropriate curricula for the level of adult education within an activity. Until this is achieved, this can only add to the helplessness of the educator role.

Brookfield (1985, 1986) believed self-directed learning involves a process of internal change in consciousness for

the learner. Central to this process is critical reflection, also known as critical thinking. Brookfield criticized those who fail to recognize the internal happenings in addition to the external behaviours of self-directed learners.

Critical Thinking

In addition to self-directed learning, Brookfield (1987) has explored the concept of critical thinking as a component of adult learning. He defined critical thinking as an activity undertaken by all individuals as part of normal development. It occurs whenever we question our underlying assumptions and investigate possible alternatives to our ways of thinking and acting. Brookfield described five characteristics of critical thinking. They are summarized below:

"Critical thinking is a productive and positive activity" (Brookfield, 1987, p. 5). Critical thinkers are people actively involved in life. They are innovative, open-minded, and they appreciate creativity. They recognize opportunities and the potential for change and have the self-confidence to take action.

"Critical thinking is a process, not an outcome" (p. 6). It is an active process of continually questioning assumptions. It is not a stage that one completes as there is no end point for complete critical development.

"Manifestations of critical thinking vary according to the contexts in which it occurs" (p. 6). A wide variety of signs may indicate the critical thinking process is happening. The event, environment, and personal characteristics of the individuals involved affect whether critical thinking is noticeably visible.

"Critical thinking is triggered by positive as well as negative events" (p. 6). A tragedy as well as a joyful event can cause people to question their assumptions and re-evaluate their role and meaning.

"Critical thinking is emotive as well as rational" (p. 7). Challenging previously accepted ideas, beliefs and behaviours is anxiety-provoking for most individuals. Feelings of resistance, confusion, uncertainty, joy, and relief are often part of the process at some point.

Generally, everyone engages in critical thinking at some point in their lives. The amount and extent of critical thinking may vary from person to person. If we did not ever use our critical thinking abilities we would live by previously established rules and standards and nothing would ever change. This would have a profound effect on individuals and society as a whole.

Brookfield (1987) emphasized four components of critical thinking. The first is identifying and challenging assumptions. This component is central to the critical thinking process. This occurs when people examine their

patterns of thinking and behaviour to reveal their underlying values and assumptions. They then begin to question these assumptions and wonder if they are still effective given what is happening in their lives.

The second component is understanding the importance of context to critical thinking (Brookfield, 1987). This is a major outcome of identifying and challenging assumptions. Contextual awareness comes from the realization that there are many possible influences, some less obvious than others, that shape our interpretations and assumptions. For example, culture and history influence many of our assumptions. "Critical thinkers are aware that practices, structures, and actions are never context-free" (Brookfield, 1987, p. 8). When we appreciate the context in which our assumptions are framed we can fully understand our actions and beliefs.

The third component of critical thinking is to imagine and explore alternatives. This involves searching for ideas and actions that will have greater meaning for the individual. This is possible when people understand that alternative ways of thinking and acting exist. This realization can be liberating because we see there are other options available to replace beliefs or behaviour with which we are dissatisfied. It can also be a threatening experience to admit that we may have misplaced trust and meaning in our beliefs.

The fourth and last component of critical thinking is reflective skepticism. We develop reflective skepticism when we become suspicious of the validity of claims made by others. Justification such as "because that's the way it is" is not taken for granted but rather is challenged and tested.

Brookfield (1987) described five phases of the critical thinking process: the trigger event, appraisal, exploration, developing alternative perspectives, and integration. It is necessary to move through all five phases for change to occur.

The trigger event is an unexpected happening, positive or negative, that initiates a sense of inner discomfort or disequilibrium in one's life. Some events are more shocking than others and therefore the critical thinking process may begin without the individual being aware of the process. A policy change at work, the beginning of a new relationship or the diagnosis of a life-threatening illness are examples of trigger events.

Appraisal is the time period following the trigger event during which self-examination occurs. This involves further examination of the event and its meaning as well as the impact upon the individual. It may also involve partial denial of the event and a search for others in a similar situation.

Exploration begins once the realization of a discrepancy present in some aspect of life has occurred. This starts the search for new ways of explaining or coping with the disequilibrium caused by the event. During this phase alternative ways of thinking or acting are tested to help reduce the level of discomfort felt by the individual.

Alternative perspectives are developed following the testing and exploration of new options. Perspectives are selected from those assumptions that have been found to be the most congruent with our lifestyle and quality of life. The adoption of new assumptions often means abandoning old ones that are no longer appropriate or of value. This part of the phase may be difficult for some individuals, depending on the circumstances.

Integration is the final stage in which the newly acquired perspectives are accepted into our way of life. This occurs once the worth and validity of the new perspectives have been established.

Contact with other individuals plays an important role in the critical thinking process (Brookfield, 1987). The process can be disturbing and unsettling for some individuals. It can also generate confusion and doubt. Therefore the presence of family, friends, or professionals can provide the opportunity for discussion and emotional release. The assistance of others can help alleviate some of these feelings and add clarity to the situation. There

are usually several opportunities for education and guidance during the process that will help to encourage and support the critical thinker.

Brookfield (1987) suggested some effective strategies for facilitating critical thinking in others. The first strategy is to affirm the learner's self-worth. It is important not to threaten the learner's self-concept. Second, attentive listening to verbal and nonverbal cues can help to understand the person's perspective and where he/she is at in the process. Brookfield suggested that one show support for such efforts. Beginners in particular need support when challenging assumptions they have held all their lives. Fourth, it is helpful to reflect back to the learners their attitudes and rationalizations. This is an effective communication skill for providing clarity. Lastly, facilitators of critical thinking should support social networking among critical thinkers and encourage regular evaluation of their progress.

Motivating people to think critically and raising their awareness of how to learn the process is an important task. Role models play a key part in fostering the desire and potential for change to occur. When offering guidance, consideration of the context is crucial to identifying the most effective ways of assisting individuals to realize their ideas and the alternatives available.

Patient Decision Making

The role of patients in medical decision making has become increasingly important. Generally, research has indicated that more and more patients prefer to be informed and involved, at least to some extent, in decisions regarding their own care. The traditional role of the patient has faded and a contemporary role emerged. The traditional role conceptualized the patient as the passive recipient of care with an unquestioning belief that the physician knew best for the individual. The contemporary role allows for increased patient participation in the management of his or her own health care while acknowledging individuality and personal preference. This provides the client with the information and, under appropriate circumstances, the opportunity to participate in decisions regarding care.

Oncology health care professionals are often confronted with treatment decisions that will have an impact on the patient's quality of life. In these instances both the risks and benefits must be considered and a choice made with the patient's best interest at the centre of the issue. Who is better able to provide the necessary insight into a patients's desired quality of life than the patient? As a result, the concept of shared decision making, also referred to as shared control, between the patient and health care team is now practised more often than ever before. Many

studies have investigated patient participation and decision making including the preferences of oncology patients in particular. From these studies certain themes have emerged.

Several studies have indicated that the majority of patients prefer to share treatment control with their physicians (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Hack, Degner, Farber, & McWilliams, 1992). Degner and Russell (1988) measured the preferences for treatment control among 60 adult oncology patients at two cancer centres in Manitoba. Their results indicated that patients wanted to be involved in the treatment decision-making process and that joint control between the patient and physician was preferable. More than half of this sample consisted of women with breast cancer.

It is apparent from the literature that when referring to shared decision making there is a range in the degree of participation patients desire. Although a standardized definition has yet to be developed and recognized for shared decision making and treatment control in the health care context, it can be said that this concept refers to mutual discussion and negotiation between the patient and the health care team with neither party having exclusive control.

Another finding from the research is that those patients who prefer the more active role are often female, younger and well-educated (Hack et al., 1992). Cassileth

et al. (1980) studied patients' preferences for active versus passive participation in their medical care and desire for treatment-related information. In a sample of 256 cancer patients, both outpatients and inpatients, the majority welcomed more information and the opportunity to play an active role. In particular, younger and more educated patients preferred to participate in treatment decisions while older and less educated patients preferred to have the physician make those decisions. Blanchard, Labrecque, Ruckdeschel, and Blanchard (1988) examined the interactions between 89 cancer patients and five medical oncologists and found that those who chose an active role in decision making were female and younger in age versus those who wanted to remain passive. Degner and Sloan (1992) also discovered that those cancer patients who preferred active involvement were younger, well-educated and were often women with a reproductive cancer such as breast cancer. In addition, there was some evidence that patients who were separated, divorced, or not married were more likely to desire an active role in treatment decision making (Blanchard et al., 1988; Ende, Kazis, Ash, & Moskowitz, 1989).

The literature also revealed that patients offered participation in treatment decisions show better psychological adjustment than patients not given a choice (Hack et al., 1992). Ende et al. (1989) found that the more

actively involved patients were more satisfied with their medical care and how their decisions were being made. Owens, Ashcroft, Leinster, and Slade (1987) concluded that offering women with breast cancer a choice between surgical treatments was important for positive psychological adjustment. Morris and Ingham (1988) conducted an experimental design study with early stage breast cancer patients referred for surgical treatment and their husbands. The experimental group was offered the choice between a mastectomy and breast conserving surgery plus radiation. Regardless of the type of surgery chosen, the women and husbands in the experimental group demonstrated overall better psychological adjustment to the cancer experience than the control group. The results from Morris and Royle (1988, cited in Hack et al., 1992) and Fallowfield, Hall, Maguire, and Baum (1990) also indicated that breast cancer patients who were offered a choice between surgical treatments experienced less anxiety and depression than those not offered a choice. Dennis (1990), when studying a group of patients with mixed diagnoses, found that cancer patients in particular desired active involvement in decision making and that information helped reduce anxiety and uncertainty.

Increased patient participation may improve patient compliance and hope for a favourable outcome (Hack et al., 1992). Cassileth et al. (1980) found that patients who were

actively involved in their own care were significantly more hopeful about their situation. This provides support for health care professionals to help patients to become well-informed and to be less fearful of the risk of increasing patient anxiety. However, some exceptions do apply.

It is important to note that these studies also found that some patients do not want to participate in treatment decision making; however, the literature provided much support that young women with breast cancer are among those who do desire a more active role in their treatment decision making.

Following this, it is important to offer patients the option to participate and not assume that they desire an active role. Hack et al. (1992) found that physicians may misperceive the degree to which patients want to participate in decision making. Strull, Lo, and Charles (1984) also reported physicians often overestimate the extent of involvement patients desire. In addition, a few studies comparing the opinions of cancer patients to healthy adults have found that healthy adults are more likely to claim preference for active involvement in treatment decision making than those faced with life-threatening disease (Degner & Sloan, 1992).

Hack, Degner, and Dyck (1994) studied 35 women with early stage breast cancer and found that patients who desired an active role in treatment decision making also

desired detailed information; however, the relationship for those patients who preferred a passive role was not clear. Cassileth et al. (1980) found a strong correlation between preference for information and desire to participate in decisions suggesting that these two components represent one approach. However, conflicting results come from a study by Ende et al. (1989) involving 312 medical patients. They found no correlation between patients' decision making and information seeking preferences. To provide clarity for this paper, I have not assumed that a patient's desire for information is the same as a patient's desire for participation in treatment decision making. This accounts for situations in which a patient wants to be informed yet prefers that the physician maintain control of treatment decisions.

The only study I found that investigated the factors that affect treatment decision making for women with breast cancer was conducted by Ward, Heidrich, and Wolberg (1989). Twenty-two women aged 38 to 77 years were offered the choice between surgical treatments. Two factors were found significantly different between the women who chose breast conservation surgery and those who chose a modified radical mastectomy. The factors were concerns about body integrity and radiation therapy respectively. In addition, these women reported that participation in decision making was important to them and they rated people sources of

information as more important than written or visual. The method of information presentation was a verbal description given by the surgeon, followed by a videotape presentation, then a handout, and lastly review of the information by a nurse. It is important to note that an interactive decision instrument was not used.

This literature represented both quantitative and qualitative research done in Canada and the United States since 1980. Almost all of these studies involved women with breast cancer and several reported on young women with early stage breast cancer. In some cases limitations such as small sample size, wide age range, variety of disease sites, multiple presenters of information, mortality bias, and selection bias were noted. Despite this the results remained fairly consistent.

The effect of framing, with regards to decision making, has been investigated in the literature. Framing refers to the context in which information is presented in terms of wording and phrasing. O'Connor, Boyd, Tritchler, Kriukov, Sutherland, and Till (1985) found that the framing of facts and scenarios influenced people when the medium used and characteristics of the interviewer did not. Their sample consisted of nursing students, patients, family members, and the general public who, when asked to compare positive and negative framing of treatment scenarios, chose the treatment that included the use of the term "survive" versus "death."

The presence of the term "survive" was found to be the major source of framing bias. However, this bias can be controlled by presenting treatment options using the same framing pattern. It is noted that only a portion of this sample were oncology patients and patient perspectives vary from those of non-patients.

O'Connor (1989) also found cancer patients' preferences to be influenced by framing and level of probability, that is chance of survival or death. In addition, this study noted a significant difference between the choice of toxic therapy by cancer patients versus those of healthy subjects. Cancer patients chose treatment more often even if the survival benefit was minimal. Other studies have often used samples of healthy people.

Siminoff and Fetting (1989) found no significant associations between the framing of treatment outcome and the type of treatment chosen with a sample of breast cancer patients. The physician's treatment recommendation was the strongest indicator of treatment decision.

The literature about the effect of framing on decision making is inconclusive. A mix of positive and negative framing was used within the description of each chemotherapy regimen on the decision board and in the script.

Decision-Making Behaviour

Two studies examined the patterns of behaviour demonstrated by women with breast cancer involved in treatment decision making.

Hilton (1994) investigated family decision-making processes about treatment (surgery, radiation, and chemotherapy) for early stage breast cancer. Using a qualitative approach, 55 women with breast cancer and their families were followed to reveal four patterns of family decision making: defer to physician; minimal exploration; joint engagement; and extensive, deliberate examination. They are listed in order from the lowest to the highest degree of participation in care.

Pierce (1993) conducted a qualitative study to investigate the decision-making experience of 48 women with early stage breast cancer when given a choice between two surgical treatments. Using grounded theory she described three styles of decision-making roles: the deferrer, delayer, and deliberator.

Subjects in the deferrer group appeared to be drawn towards one particular option. These women made quick, conflict-free decisions, often following what they perceived to be the physician's recommendation. Usually the decision was made without considering all the attributes of each option. Although they accepted responsibility for making their decision, they often deferred the responsibility for the outcome onto the physician, fate, or God. They declared

a preference for their choice based upon immediate appeal with no deliberation or search for other sources of information. This group was averse to risk and, regardless of choice, felt they had chosen the safest method. The decision experience was simple and straightforward. Subjects reported that there was no decision because they had not considered the other option. They did not know how they made their choice and many did not believe they had made a choice. Patients reported satisfaction with their decision and did not anticipate regret later. Subjects in this group were the oldest in age and accounted for 41 percent of the sample.

Subjects in the delayer group considered at least two options and separated the information into manageable parts. Their deliberation is described as random and superficial as they often jumped from the consideration of one option to another. The women appeared to respond to a particular aspect of each option rather than to the total picture. They compared the two choices until the first difference between them was perceived and then a decision was made. Subjects were satisfied with their decision. This group was also averse to risk and information sought was usually of the popular variety such as magazines. Subjects in this group were younger than the deferrers and accounted for 44 percent of the sample.

Subjects in the deliberator group "expressed a personal responsibility for making a quality decision" (Pierce, 1993, p. 26). These women were unique because their action was purposeful, using a strategy or plan. They also considered risk, expressed confidence in the decision-making process, yet had lingering uncertainty about the outcome and anticipated regret at some point in the future. Their mental strategy involved laying out a plan to look at the attributes of each alternative. This was followed by an extensive information search including expert consultation. A decision was made only when the subject was confident she had considered all relevant information and found an alternative that satisfied her major requirements. These subjects sought control and identified events beyond their control. They did not experience immediate satisfaction with their decision but rather described a feeling of confidence with the process. The women in this group experienced by far the most psychological distress and accounted for 15 percent of the sample.

The results from Pierce's study are enlightening as she is the first to try to describe the decision-making behaviour of women with breast cancer. Limitations such as age, physician presentation and the small sample size were noted. The wide age range, 25 to 90 years, could account for different preferences of surgical treatment as well as approaches to decision making. The presentation of

information by the physicians was not controlled and therefore likely varied from physician to physician. Also, without a standardized format, the presentation of information was possibly influenced by patient characteristics such as age and everyday variability from situation to situation.

The Decision Board

In the past, health professionals have attempted to use a variety of presentation methods and designs for the purpose of patient education. In a study conducted by Miller and Shank (1986), the effectiveness of three different methods of presenting patient educational material were compared. Their findings suggested that the presence of a health professional to present and review information with the patient is an effective method in terms of patient learning, information retention and compliance.

The concept of a decision board was developed at the Hamilton Regional Cancer Centre only within the last few years; therefore, the literature available is very limited. The decision board was developed to present information obtained from clinical trials, with respect to quality of life, to patients to encourage the process of shared decision making regarding treatment options.

The first decision board was developed to describe treatment information to patients with Stage I breast

cancer. Specifically, the board was designed to objectively present the risks and benefits of chemotherapy to an individual. As the result of a simple process, an informed patient could make a personal choice (Levine et al., 1992). The patient's choice was "chemotherapy" or "no chemotherapy." For women with Stage I disease chemotherapy provides a modest benefit, perhaps, at the risk of greater side effects. The board presented information on the possible outcome and quality of life for both options. The instrument was proven to be reliable and valid with a sample of 30 healthy volunteers (Levine et al., 1992). Reliability was tested by administering the same board to the same subjects on two separate occasions. Following each presentation the subject was asked to indicate the strength of her preference using a Likert scale. In between the reliability tests, validity was evaluated by changing the information about risks and benefits to determine whether preferences changed in a predictable manner (Levine et al., 1992).

The second decision board was also developed to describe treatment information to patients with Stage I breast cancer but, in this case, for those eligible for radiotherapy. This board presented the advantages and side effects of radiation treatment, as well as the outcome and effect of treatment on long-term survival. The patient's choice was "radiation" or "no radiation." The choice of

radiation therapy offered no survival advantage but rather an increased chance of avoiding a recurrence of cancer in the breast and subsequent surgery (Whelan, 1993). The researcher using this board investigated the gap between information provided by the physician and patient understanding.

Summary

This review of the literature has demonstrated that self-directed learning and critical thinking are important goals of adult education in general. In recent years adult education has taken on an important role for patients as consumers within the health care system. In many ways patients have been allocated greater responsibility for their own care. As the number of people diagnosed with cancer continues to grow so has the concern for quality of life. As a result there are an increasing number of opportunities for patient education so that in some situations they may have the chance to participate in their treatment decisions. One aspect of understanding how people make decisions and think critically regarding their health is to inquire about what issues are most important to them. The intent of this study was to investigate what factors affect the treatment decision-making process for women with breast cancer.

CHAPTER THREE: METHODOLOGY

The purpose of this research project was to examine the factors that influence the decision made by a woman with breast cancer when given a choice between two chemotherapies. To further understand the decision-making process each individual's learning and quality of life were investigated.

Design

The study followed an empirical-analytical research paradigm. This quasi-experimental design involved a two-group comparison using survey data.

Sample

The study sample was 30 premenopausal women newly diagnosed with Stage II breast cancer. The sample was recruited from the new patient clinic at the Hamilton Regional Cancer Centre for 26 consecutive weeks. Up to three new patients (of any age), per physician, were seen in this clinic weekly on Thursdays. Three medical oncologists regularly worked in this new patient clinic with the help of other medical and nursing support staff.

Eligibility criteria were as follows:

A diagnosis of Stage II breast cancer;

Premenopausal status;

Post-surgery for removal of breast cancer;

English speaking and fully literate; and

Written consent to comply with completing questionnaire.

Instruments

The instruments used for this study were a decision board and a questionnaire. They are included in Appendices A and B.

The decision board design somewhat followed that of the two previously developed boards. The content was chosen by me with input from the staff of the breast clinic. It was based upon the literature and my own clinical experience in attempting to meet the informational needs of patients and their families. Prior to implementing the decision board, feedback was obtained from several nurses and physicians at the Cancer Centre as well as other patients with breast cancer. A written script was developed to accompany the decision board (see Appendix C). The script was tested and found to be at a Grade Eight readability level using the SMOG test (Redman, 1988).

The questionnaire was mainly quantitative in design with four sections: The first included demographic information; the second was about how and why each woman made her decision; the third tested learning from the decision board; and the fourth gathered baseline information about quality of life. The questionnaire was original

except for section four, The Functional Assessment of Cancer Therapy Scale by Cella, Tulsky, Gray, Sarafian, Linn, Bonomi, Silberman, Yellen, Winicour, Brannon, Eckberg, Lloyd, Purl, Blendowski, Goodman, Barnicle, Stewart, McHale, Bonomi, Kaplan, Taylor, Thomas, and Harris (1993). The authors reported coefficients of reliability and validity that were uniformly high. Quality of life item numbers 8, 16, 19, 25, 33, and 43 were excluded from data analysis because during questionnaire administration many subjects verbalized some uncertainty about how to interpret these statements. Inter-item correlations are reported in Appendices D and E.

In an effort to take into account order of presentation, two versions of the decision board, the script and the questionnaire, were administered to patients. These are labelled "Version One" and "Version Two" and can be found in Appendices A and F. This was done to determine whether the order in which the chemotherapy options were presented affected patients' choices. Appropriate changes were made to the script and questionnaire to coincide with the decision board version used.

Pilot Test

A pilot test was performed using seven healthy volunteers and four new patients. This was to ensure that the information on the decision board and questionnaire were

understandable. All individuals chosen had not been exposed to this information previously. All subjects were administered Version One of the decision board and questionnaire.

The volunteer group consisted of seven women aged 25 to 44 years of age. These individuals varied with regards to marital status, number of children, employment, level of income, education, and religion.

The volunteers were administered the decision board on two separate occasions between one and three weeks apart in a home or work setting. Immediately following the presentation each woman was asked to complete the questionnaire, sections one, two, and three only. Therefore, each volunteer completed the questionnaire twice. The volunteers were not asked to complete section four of the questionnaire because the reliability and validity of the quality of life tool was previously established (Cella et al., 1993).

Of these seven women, three chose AC and four chose CMF. All commented on finding the decision board helpful and the information clear and concise. Every volunteer answered all the learning questions correctly and a variety of reasons were given for their choice of chemotherapy.

The patient group consisted of four premenopausal women newly diagnosed with Stage II breast cancer seen at the Hamilton Regional Cancer Centre following surgery. They

ranged in age from 36 to 46 years of age. This group also varied with regards to marital status, number of children, employment, level of income, education and religion.

I presented the decision board to each patient in one of the clinic rooms following her consultation with the medical oncologist. Each woman was given a copy of the information to take home and asked to return one to two weeks later with her decision made. At this time each woman was asked to complete the entire questionnaire. Therefore, each patient was administered the board and asked to complete the questionnaire once.

Of these four women, two chose AC and two chose CMF. Three women provided feedback indicating the decision board had been helpful and one woman commented that she preferred to receive an oral explanation alone rather than a combined oral and visual presentation. Each patient answered at least six out of the eight learning questions correctly, a 75 percent level of correctness, and again a variety of reasons were given for each person's choice of chemotherapy.

This pilot test provided some evidence towards establishing internal consistency and content validity since the volunteer group's questionnaire answers remained consistent on the first and second presentation; and, all pilot subjects appeared to interpret the questions and information as intended. I recognize that reliability and validity cannot be established due to the limitations of

using this small sample size. In a larger study over an extended period of time, one could attempt to test for stability and internal consistency.

Procedure

Permission to proceed with this study was obtained from Dr. Hal Hirte, Chairperson of the Protocol Review Committee at the Hamilton Regional Cancer Centre and Dr. Peter McCulloch, Chairperson of the Institutional Review Board for the Hamilton Civic Hospitals.

In the new patient clinic, I, the researcher, and clinic staff together identified potentially eligible participants. My original goal was to see each patient, as a clinic nurse, to obtain each woman's health history and, if time allowed, to perform a physical assessment. However, due to time constraints and the number of eligible clients present in the clinic on some Thursdays, it soon became evident that this was not going to be possible. As a result, I saw most women for the presentation of the decision board only. When this was the case, the history and physical were performed by a medical oncologist, an oncology resident or another nurse. All of these health care professionals were instructed, prior to seeing a patient, not to comment or release any information about the two chemotherapy regimens.

Following the history and physical, the medical oncologist saw the patient to give the recommendation for chemotherapy. Also at this time the medical oncologist informed the patient about this study, the use of the decision board, questionnaires, and the written consent form. A copy of the consent form is found in Appendix G. Every patient approached agreed to participate. Next I, alone, presented the decision board to each woman to explain the two treatment options. On approximately three occasions I was accompanied by a medical student or another nurse who sat in on the presentation but remained silent.

It is important to note that in twenty-nine of thirty cases the patient was accompanied to their clinic appointment by one to three family members or friends. These individuals were encouraged to listen to the decision board presentation with the patient and were given the opportunity to ask questions.

The decision board presentation began with the board empty except for the headings "Chemotherapy," "Treatment A," and "Treatment B." The process involved reading aloud the print contained on five cards and explaining two bar graphs, each contained on a separate card, for a total of seven cards. The board was designed in three sections, the first provided general information about chemotherapy, the second described each treatment schedule and the third displayed the incidence of the side effects, nausea, vomiting, and

hair loss, associated with each regimen. After a brief introduction to the decision board, I read each card aloud and placed it on the board using velcro. After all seven cards had been discussed and placed on the board, I proceeded to give some additional information about each regimen. These details are contained in the script and were thought to be relevant and important for the patient to know prior to making a decision. They were not included on the face of the decision board because of space limitations and my concern about the board appearing overwhelming and crowded with information.

The patient, with her family or friends was invited to ask questions after each section. The time required to administer the decision board ranged from 15 to 35 minutes depending upon the number of questions asked.

Each patient was told that she need not make a decision during this clinic visit but would be given a copy of the information to take home and consider. Every woman left the clinic with an 11" X 17" copy of the decision board as well as a copy of the written script.

Every woman was given a return appointment for one or two weeks later. She was asked to return to the clinic with her decision made. In four cases return appointments were delayed later than two weeks. Reasons for this were a planned vacation for one woman, further surgery was required for another, and a time delay in clarifying test results for

another woman. Also, one patient decided on no treatment and did not return for her next appointment. Her questionnaire was mailed to her home and she completed it and returned it promptly.

All patients were seen in the clinic in one of eight very similar examining rooms.

Upon the patient's return visit, I was the first to see each woman in one of the eight examining rooms. The patient was asked to state her preference for chemotherapy and offered the opportunity to ask any questions related to her choice. At that time I asked each woman to complete the questionnaire. If the patient had brought a friend or family member to the clinic with her, the individual was asked to return to the waiting room until the patient was finished filling out the questionnaire. Therefore, each woman completed the questionnaire alone in an examining room. The time required to complete the questionnaire ranged from 10 to 25 minutes. Once the questionnaire was completed each woman was then seen by myself and/or the attending medical oncologist and the friend or family member was invited back into the room. The discussion that then took place involved reviewing test results, deciding when to begin chemotherapy, reviewing details of the chosen treatment regimen and further patient teaching around the chemotherapy treatment process.

Most women were seen in the clinic by the researcher before every chemotherapy treatment. Therefore, there was continued contact between the researcher and the study participants. It is the current standard practice for a nurse and physician to see patients in the clinic prior to the administration of chemotherapy. This is to assess the patient's physical status, to allow for questions to be asked and for the discussion of any problems or side effects from treatment.

The participants for this study were seen during their regular clinic visits. The only inconvenience to them was the time and energy required to complete the questionnaire. There were no anticipated physical or psychological risks to the participants.

Limitations

Perhaps the most obvious limitation of this study was the lack of a control group. It is recognized that an experimental design would have provided evidence about the efficacy of the decision board; however, it is believed that the decision board has been established as a useful educational tool. Therefore, from an ethical standpoint, a patient should not be denied access to this method of presenting information.

In addition, the use of qualitative methods of data collection may have provided more detailed information and

led to a greater understanding of patient choices and influencing factors.

Another limitation of this study was the specific population to which the patients belonged and the treatment choice applied. This population of women comprises approximately 15 percent of all breast cancer patients; therefore, the results are not generalizable to all women with breast cancer. Also, subject recruitment took longer than anticipated. Due to time constraints, subject recruitment stopped when the sample size reached 30 subjects; therefore, when interpreting the significance of any results one must consider the small sample size.

Given the population, time constraints, and questionnaire design, I was unable to test for other forms of reliability and validity.

Attempts were made to control the patient environment and procedure as much as possible. A limitation, beyond my control, was who the patients spoke to or sought information from between appointments may have swayed their decision. As a result, it is suspected that some women made their choice based upon information from sources other than the decision board.

This clinic was a busy site with many health care professionals present at one time. Nurses, physicians, and rotating residents and medical students kept me busy

ensuring that everyone was informed about this study so as to limit the chance and incidence of contamination.

Data Analysis

Descriptive statistics were calculated for all questionnaire items, including measures of central tendency and variability. Correlations were used to further examine the relationships among the demographics, learning questions, factors affecting decision making, and quality of life.

The t-test was used to compare the means of the women who were randomly assigned to the two different versions, as well as those who chose AC versus those who chose CMF. A multivariate analysis of variance could not be performed due to the small sample size and the number of variables. Scale totals could not be calculated as many of the inter-item correlations were low.

The chi-square test was used to answer the third and fourth sub-questions to compare the frequencies of responses for the non-parametric data. The data from the two women who chose no treatment are analyzed and reported on as part of the whole sample only. They are not reported on as a separate treatment choice group since trends cannot be determined from a sample of two.

The results of these analyses are presented in Chapter Four.

CHAPTER FOUR: RESULTS

The purpose of this study was to investigate the factors affecting the decision-making process for premenopausal women with Stage II breast cancer when given a choice between two chemotherapy regimens. Questionnaire responses from those who chose AC were compared to those who chose CMF. Descriptive and inferential statistics are presented in this chapter.

Descriptive Statistics

Demographic data for the participants are summarized in Table 1. Thirty women participated in the study. The mean age of participants was 45.7 years, with ages ranging from 35 to 52 and having a median of 48 years. Twenty-four women were married, four had never been married and two were divorced. Twenty-three (77 percent) had one or more children. The largest proportion had one or more children 11 to 15 years of age. In addition, 15 women said they would have help caring for their children some or all of the time while 14 answered not applicable.

Nineteen (63 percent) were employed. Nine (30 percent) were professionals or senior management, 11 were skilled workers, five clerical and five unskilled including homemakers who did not claim to have any additional training. This classification scale was adapted from Employment & Immigration Canada, 1993.

Table 1

Demographics

N = 30

Variable	Mean	Median	Range
Age	45.7	48.0	35-52 years

	N	%
Marital		
Never married	4	13
Married	24	80
Separated	0	0
Divorced	2	7
Widowed	0	0
Children		
A child of any age	23	77
Under 5 years	1	3
5 to 10	6	20
11 to 15	10	33
16 to 19	8	27
20 to 24	9	30
25 and over	7	23
Child Care		
Yes, all or most of the time	12	40
Some of the time	3	10
No, not at all	0	0
Not applicable	14	47
No response	1	3
Work		
Employed	19	63
Unemployed	3	10
Student	1	3
Full-time homemaker	5	17
Retired	1	3
No response	1	3
Position		
Professional/Sr. Management	9	30
Skilled	11	37
Clerical	5	17
Unskilled	5	17

(table continues)

	N	%
Income		
$0 - 10,000	1	3
$10,000 - 30,000	7	23
$30,000 - 50,000	8	27
Greater than $50,000	12	40
Not applicable	1	3
No response	1	3
Education		
University	8	27
College	4	13
High School	10	33
Other	8	27
Religious Faith		
Jewish	0	0
Protestant	13	43
Roman Catholic	12	40
None	3	10
Other	2	7
Religious Involvement		
I attend services weekly (or more often) and I am involved with my religious community and functions	7	23
I attend services weekly	2	7
I attend services occasionally	15	50
I do not attend religious services	6	20

Note: All percentages may not add up to 100 due to rounding.

When asked about family income, 40 percent indicated an income level of greater than $50,000, 27 percent answered $30,000 to $50,000, and 23 percent stated $10,000 to $30,000.

Twelve (40 percent) women had completed a post-secondary educational program with eight (27 percent) having attended university and four (13 percent) community college. A high school diploma was the highest level of education for 33 percent while 27 percent indicated "other" meaning other than high school, college or university. For the eight women who stated other, three completed up to a Grade Eight or Ten level while the other five had either pursued post-secondary programs outside of college or university or completed only part of a college program.

Two questions were asked about religion, one about chosen faith and the other about level of involvement. Forty-three percent were Protestant, 40 percent were Roman Catholic, three (10 percent) claimed no religion, two (seven percent) said other and none were Jewish. Fifty percent stated they attended their religious services occasionally, 23 percent said they attended services weekly and were involved in their religious community, 20 percent said they did not attend and seven percent said they attended services weekly.

Correlational analyses were performed on all the variables to better describe the relationships among the data (see Tables 2 and 3). Only those correlations

Table 2

Correlations of Demographics and Difficulty Rating of Decision with Other Variables

Variables	Age	Child 5-10	Child 11-15	Child 16-19	Child 25&up	Child Care	Work Position	Difficulty With Decision
Child 5-10	-.60**	1.00	---	---	---	---	---	---
Child Care	---	---	-.62**	---	---	1.00	---	---
Income	---	---	---	---	---	---	-.55*	---
Age of Children	---	-.65**	-.50*	---	---	.56*	---	---
Have Pain	-.63**	---	---	---	---	---	---	---
Friend Support	---	---	---	---	-.54*	---	---	---
Able to Work	---	---	---	---	---	---	---	.50*
Self-conscious	---	---	---	.54*	---	---	---	---

*p < .01 **p < .001

NOTE: Only those correlations significant at p < .01 are included.

Table 3

Correlations Among Factors and Quality of Life

Quality of Life Items	Factor Items: Side Effects In General	Factor Items: Maintaining Normal Routine
Feel Distant	---	.57*
Friend Support	---	-.51*
Acceptance	.49*	---

*p < .01

NOTE: Only those correlations significant at p < .01 are included.

significant at $p < .01$ are reported on. When there was little variance and the distribution extreme the correlations were not interpreted as meaningful (Coldeway, 1989). During data entry, the demographic variable "work position" was coded using a scale of one to four with professionals or those in senior management positions coded one and unskilled workers coded four. This scale is in the opposite direction to the scale used for the variable "income"; therefore, a negative correlation between work position and income means as the level of work position increased so did the level of income. Also, the factor table was coded using a scale of one to four with "very important" coded one and "not applicable" coded four. This scale is in the opposite direction to the scale used in the quality of life section of the questionnaire. Therefore, a negative correlation between a factor item and a quality of life item means the two items varied in the same direction on the scale, both low values or both high values.

A few interesting findings emerged from the correlations. The more children aged five to fifteen years a woman had, the more importantly she rated age of her children. The more children aged sixteen to nineteen years a woman had, the more self-conscious she said she was about the way she dressed. The more difficult the decision process was rated the less able she was to work. These results are presented in Table 2. In the correlations

between the factors and the quality of life items it is observed that the more importantly "side effects in general" was rated the less a woman perceived she had accepted her illness. Also, the more importantly "maintaining your normal routine" was rated the more she perceived support from friends (see Table 3).

Eight questions were asked to assess the subjects' learning and comprehension from the decision board. The responses ranged in level of correctness from 83 percent to 100 percent. This is presented in Table 4.

Within the questionnaire the women were asked if they found the decision board helpful. As can be seen in Table 5, 21 (70 percent) responded that they found it very helpful, eight quite helpful and one somewhat helpful. No one found the decision board not helpful.

Treatment choice results are presented in Table 6. Sixteen women (53 percent) chose AC while 12 (40 percent) chose CMF and two women chose not to have any chemotherapy treatment.

When asked if this decision was difficult to make the responses were varied. Five women answered "very much," six said "quite a bit," seven said "somewhat," four responded "a little bit," and, eight said "not at all" (see Table 7).

The participants were also asked if their decision was influenced by anyone and who that person was. Fifteen (50 percent) answered a family member or friend had influenced

Table 4

Learning Questions

	# Correct	%
Chemotherapy can kill cancer cells and normal cells in the body.	30	100
Normal cells can recover from chemotherapy and grow again.	29	97
AC and CMF offer the same chance of survival, they both help prevent the cancer from coming back.	27	90
AC takes 4 months to finish.	25	83
CMF means coming to the centre 12 times for treatment.	29	97
AC means getting chemotherapy through an intravenous and by taking pills.	25	83
There is a greater chance of vomiting with CMF.	27	90
There is a greater chance of losing my hair with AC.	29	97

Table 5

Helpfulness of Decision Board

Rating	N	%
Very much	21	70
Quite a bit	8	27
Somewhat	1	3
A little bit	0	0
Not at all	0	0

Table 6

Treatment Choice

Treatment	N	%
AC	16	53
CMF	12	40
None	2	7

Table 7

Difficulty Rating of Decision

Rating	N	%
Very much	5	17
Quite a bit	6	20
Somewhat	7	23
A little bit	4	13
Not at all	8	27

them. Eight women stated no one influenced them, one woman said another patient, and two did not respond. Four women chose "other" which included acquaintances, a combination of the above people, a family physician, and a friend who was an echocardiogram technician. When given the option no one indicated that a Cancer Centre nurse or physician had influenced their choice. This is presented in Table 8.

A table of 15 factors was included in the questionnaire. The women were asked to indicate the level of importance of each factor to their treatment decision. Table 9 presents the frequencies of each factor by the four point scale for the sample as a whole as well as the AC and CMF groups. The whole sample and the AC group rated "maintaining your normal routine" as "very important" the most often. The CMF group rated "side effects in general" and "vomiting" as "very important" the most often.

Four validation questions were asked to help qualify the decision and the factors stated to be most important in making that treatment choice. These are question numbers 25 to 28 in the third section of the questionnaire. The results are presented in Table 10. When asked what they would choose if the chance of hair loss was the same for both treatments 67 percent answered AC while nine (30 percent) said CMF and one did not respond. When asked what they would choose if the chance of vomiting was the same for both treatments 70 percent answered AC while 27 percent said

Table 8

Decision Influence

	N	%
A doctor at the Cancer Centre	0	0
A nurse at the Cancer Centre	0	0
Another patient	1	3
A family member or friend	15	50
Other	4	13
No one	8	27
No response	2	7

Table 9

Factor Importance by Treatment Choice

Factor Item	Whole group				AC				CMF			
	Very	Impt	Not	N/A	Very	Impt	Not	N/A	Very	Impt	Not	N/A
Side effects	16	10	2	0	4	8	2	0	10	2	0	0
Nausea	12	10	6	0	3	8	4	0	8	1	2	0
Vomiting	14	11	4	0	3	9	3	0	10	1	1	0
Hair loss	11	11	7	0	3	7	6	0	6	4	1	0
# of Needles	5	11	13	0	3	5	7	0	0	6	6	0
# of Trips	7	11	12	0	5	8	3	0	0	3	9	0
Family role	11	14	2	2	4	7	2	2	6	6	0	0
Home	11	14	5	0	4	9	3	0	6	5	1	0
Children	6	7	10	7	4	3	4	5	2	4	5	1
Family think	4	8	15	3	2	4	8	2	2	3	6	1
Friends think	2	5	18	4	1	3	9	2	1	1	8	2
Exp. of friend	7	6	5	11	1	3	4	7	5	2	1	4
Work	9	7	6	8	6	2	4	4	2	4	2	4
Finances	6	5	12	7	3	2	6	5	1	3	6	2
Routine	17	10	1	1	9	7	0	0	7	3	1	1
Other	0	1	0	0	0	0	0	0	0	1	0	0

NOTE: Those women who chose no treatment or did not respond were excluded from this table.

Table 10

Validation Questions

Altered Variable	AC		CMF		No Response	
	N	%	N	%	N	%
Hair loss	20	67	9	30	1	3
Vomiting	21	70	8	27	1	3
Duration	6	20	23	77	1	3
# of Visits	13	43	15	50	2	7

CMF and one did not respond. The same was asked for treatment duration - what if both treatments took six months to finish? Twenty-three women (77 percent) answered CMF while six said AC and one did not respond. Lastly, the number of treatment visits were questioned - what if CMF meant only one visit every four weeks instead of two for the six-month period? Participant responses were 50 percent for CMF, 43 percent for AC and two did not respond.

The quality of life section of the questionnaire included 43 items. The means and standard deviations of the responses are presented in Table 11. The items were rated according to a five-point scale in terms of how true the statement described how the individual had been feeling during the past seven days. The physical well-being items were rated fairly low according to the means for each item whereas most of the social/family and all of the functional well-being and relationship with doctor items were rated high. Items under the headings emotional well-being and additional concerns show a mix of low and high ratings.

The last frequency to report on is the women who received Version One and Version Two of the decision board and their associated treatment choice. As can be seen in Table 12, of the 15 women who were presented Version One, six (40 percent) chose AC while eight (53 percent) chose CMF and one chose no treatment. Of the 15 women who were

Table 11

Quality of Life

Item	Mean	SD
Physical Well-being:		
Lack of energy	1.27	1.02
Nausea	.14	.44
Meeting needs	.66	.86
Pain	.76	.99
Side effects	.45	.74
Feel sick	.32	.67
Time in bed	.36	.56
Social/Family Well-being:		
Distant from friends	.41	.93
Family support	3.33	1.27
Friend support	3.37	1.10
Family acceptance	3.45	.95
Family communication	.39	.83
Close to partner	3.82	.48
Satisfied with sex life	3.19	1.23
Relationship with Doctor:		
Confidence in doctor	3.79	.49
Doctor answers questions	3.86	.44
Emotional Well-being:		
Feel sad	1.62	1.27
Proud of coping	3.17	1.00
Losing hope	.14	.35
Feel nervous	1.69	1.00
Worry about dying	1.46	1.32
Functional Well-being:		
Able to work	2.86	1.16
Work is fulfilling	3.11	1.03
Enjoy life	3.31	.76
Acceptance of illness	3.10	.86
Sleeping well	2.43	1.43
Enjoying leisure pursuits	2.93	1.05
Content with quality of life	2.50	1.38
Additional Concerns:		
Short of breath	.30	.75
Self-conscious about appearance	.93	1.23
Arms swollen/tender	1.48	1.30
Feel sexually attractive	2.03	1.35
Bothered by hair loss	.43	.90
Worry about family risk - cancer	1.90	1.58
Worry about effects of stress	2.13	1.31
Bothered by weight change	.67	1.18
Feel like a woman	2.86	1.36

Table 12

Treatment Choice by Decision Board Version

	Treatment Choice					
	AC		CMF		None	
	N	%	N	%	N	%
Version One	6	40	8	53	1	7
Version Two	10	67	4	27	1	7

presented Version Two, 10 (67 percent) chose AC while four chose CMF and one chose no treatment.

Inferential Statistics

In order to answer my research questions, the t-test and chi-square test were used as well as various post hoc analyses.

The main research question was: What factors affected the decision-making process for women newly diagnosed with Stage II breast cancer when given the choice between two equally effective chemotherapy regimens? The answer to this was obtained from the women's responses to Question 22 and 24 on the survey.

Question 24 presented a table of factors where each woman indicated the level of importance of each factor to her decision. Using t-tests, five factors were found to be rated significantly different in importance by the women who chose AC and those who chose CMF (see Table 13). These were side effects in general, vomiting, hair loss, the number of treatment visits, and family role (meaning their role as a wife, mother, daughter, or sister). The CMF group rated side effects in general, vomiting, hair loss, and caring for their family (family role) as more important than the AC group. The AC group rated the number of trips to the centre as more important than the CMF group. Table 13 presents two-tailed significance.

Table 13

Comparison of Variables across Version and Treatments

Variable	# of Cases	Mean	SD	t-value	df	p
Hair Loss						
Version One	15	1.53	0.74	-2.54	27	.017
Version Two	14	2.21	0.70			
Child 16-19						
AC	16	0.13	0.34	2.25	26	.041
CMF	12	0.67	0.78			
Side Effects in General						
AC	14	1.86	0.66	-3.29	24	.003
CMF	12	1.17	0.39			
Vomiting						
AC	15	2.00	0.66	-3.04	25	.006
CMF	12	1.25	0.62			
Hair Loss						
AC	16	2.19	0.75	-2.30	25	.031
CMF	11	1.55	0.69			
# of Trips						
AC	16	1.88	0.72	3.94	26	.001
CMF	12	2.75	0.45			
Family role						
AC	15	2.13	0.99	-2.13	25	.044
CMF	12	1.50	0.52			
Sex Life						
AC	13	3.77	0.60	-2.72	22	.018
CMF	11	2.45	1.51			

Post hoc analyses were used to explore this question further. In Table 9 a breakdown of the factor table from Question 24 is provided. By combining the ratings from the "very important" column, with the ratings from the "important" column I found the three overall most important factors for the sample as a whole, including the AC group and the CMF group. This is presented in Table 14. The three most important factors to the whole group were maintaining their normal routine, followed by side effects in general and then equal ratings among vomiting, family role and maintaining their home. The AC group rated maintaining their normal routine as most important, followed by the number of trips and maintaining their home, and then vomiting and side effects in general. The CMF group responded that side effects in general and family role were the most important followed by vomiting and maintaining their home, and then hair loss and maintaining their normal routine.

To further investigate the meaning of the number of trips as an important factor, I examined where each woman lived in terms of distance from the Cancer Centre. I wondered if perhaps those who had chosen AC lived further away than those who had chosen CMF. This was not the case since I found women from both groups lived in Burlington, Dundas, Ancaster, Caledonia, Milton, Oakville, Acton, Brantford, and Hagersville.

Table 14

Three Most Important Factors by Treatment Choice

Factors	Whole Group	AC	CMF
First	Maintaining normal routine	Maintaining normal routine	a. Side effects in general b. Family role
Second	Side effects in general	a. Maintaining home b. # of trips	a. Vomiting b. Maintaining normal routine
Third	a. Vomiting b. Family role c. Maintaining home	a. Vomiting b. Side effects in general	a. Hair loss b. Maintaining home

Question 22 was open-ended and asked each woman to list the top three reasons for her choice. A total of 75 reasons were given which resulted in a mean of 2.5 reasons given per person. To analyze these data a list of responses was compiled and each response was classified into one of nine categories. These categories were established by me based upon the reasons given by the women (see Table 15). The categories are presented in order from the highest to lowest number of responses.

The quality of life category included reasons relating to the physical and psychological effects of treatment as well as comments made about maintaining or returning to normal or wellness. Eighteen reasons regarding quality of life were given, nine from the AC group and nine from the CMF group.

Time referred to overall treatment duration. All sixteen women who chose AC named time as a reason for their decision. Time as a reason for choice was not stated by anyone who chose CMF.

Side effects included statements where the term "side effects" was used, as well as, vomiting, hair loss, nausea, and heart effects. Side effects in general and vomiting were stated six times each, once from the AC group and five times from the CMF group. Hair loss was given as a reason six times, all from women who had chosen CMF. Nausea was given twice, both from women who had chosen CMF. Effects on

Table 15

Reasons for Choice by Treatment

Reasons for Choice	Whole Group	AC	CMF
Quality of Life	18	9	9
Time	16	16	0
Side Effects:			
In General	6	1	5
Vomiting	6	1	5
Hair loss	6	0	6
Nausea	2	0	2
Heart Effects	1	0	1
Family Concerns	6	2	3
Treatment Schedule	4	2	2
Treatment Efficacy	4	2	1
# of Trips/Distance	3	3	0
Work	2	2	0
Influence of Others	1	0	1
Total	75		
Mean of Total	2.5		

the heart was given as a reason once by a woman who had chosen CMF.

Family concerns took into account reasons that mentioned children, husbands or parents. Six reasons were given related to family, two from the AC group, three from the CMF group and one from a woman who had chosen no treatment.

Treatment schedule included comments about the number of treatments, intravenous starts, needle pokes and monitoring by health care professionals throughout treatment. Four reasons were given relating to treatment schedule, two from women who had chosen AC and two from women who had chosen CMF.

Treatment efficacy included statements in which one treatment was thought to be better than the other. Four reasons about efficacy were given. Two of the four reasons came from a woman who had chosen AC. She had sought outside medical opinions about chemotherapy and believed AC was better. One reason was given by a woman who had chosen CMF and the other from someone who had chosen no treatment who was pursuing alternative homeopathic and naturopathic treatments.

Number of trips and distance included reasons referring to transportation and the number of trips or visits. Three reasons were stated within this category, all from women who had chosen AC.

Work referred to employment reasons. Two statements were made regarding work as a reason for their choice, both from women who had chosen AC.

The influence of others referred to one woman who stated the opinion of her family physician was one reason for her choice. This person had chosen CMF.

For the whole sample the most common reason given for their choice was quality of life. This was followed by time and then an equal number of references to side effects in general, vomiting, hair loss, and family concerns. The AC group gave time as the most popular reason followed by quality of life and then the number of trips. The CMF group stated quality of life as their most common response followed by hair loss and then an equal number of responses related to side effects in general and vomiting (see Table 16).

To further investigate the importance of four factors in particular, hair loss, vomiting, treatment duration, and the number of trips, the chi-square test was used to check for significant differences between the number of responses given by the AC and the CMF groups to the validation questions. A significant difference was found between how the AC group and the CMF group answered all four questions. This is shown in Table 17. For example, when asked what they would choose when the chance of hair loss was the same for both treatments, 15 out of 16 women in the AC group

Table 16

Three Most Important Reasons by Treatment Choice

Factors	Whole Group	AC	CMF
First	Quality of life	Time	Quality of life
Second	Time	Quality of Life	Hair loss
Third	a. Side effects in general b. Vomiting c. Hair loss d. Family concerns	# of Trips	a. Side effects in general b. Vomiting

Table 17

Validation Questions by Treatment Choice

Choice	Hair Loss AC	Hair Loss CMF	Vomiting AC	Vomiting CMF	Duration AC	Duration CMF	# of Trips AC	# of Trips CMF
AC	15	1	15	1	6	10	13	2
CMF	4	8	5	7	0	12	0	12
	$\chi^2 = 12.16$ $p < .002$		$\chi^2 = 9.71$ $p < .008$		$\chi^2 = 6.15$ $p < .046$		$\chi^2 = 21.03$ $p < .001$	

indicated they would stay with AC while one woman would have changed her mind and chosen CMF. In the CMF group, eight remained with their original decision while four women would have changed their mind and chosen AC. This change accounts for those women who chose CMF related to less chance of hair loss. These results support the factors rated as important to the treatment decision and the reasons stated for the choice.

The t-test was also used to examine the effect of the order of presentation of the two treatments on the decision board. The only variable rated significantly different between the women who received Version One of the decision board and those who received Version Two was hair loss (see Table 13). Hair loss was rated more important in terms of treatment choice by the women who received Version One. Therefore, since hair loss was also a factor rated significantly more important by the women who chose CMF than those who chose AC, it must be considered a possibility that the position of hair loss in the side effect section on the decision board may have had an effect on choice. Of the women who received Version One, eight chose CMF and six chose AC.

What and how much learning occurred when the decision board was used to convey the information about each regimen? On the eight learning questions scores ranged from 83 percent to 100 percent correctness. There were also no

significant differences found between the responses of the two groups on these questions with the use of t-tests.

Were there significant differences in the quality of life experienced by women who chose one chemotherapy regimen or the other? Using t-tests only one quality of life item was found to be rated significantly different by the women who chose AC versus those who chose CMF. The item was "I am satisfied with my sex life" and was rated higher in agreement by the women who chose AC (see Table 13). This is further supported by the item "I feel close to my partner" which approached significance for being rated higher in agreement by the women who chose AC. This result may have occurred by chance because of the number of statistical tests performed.

Were there significant demographic differences between the women who chose one chemotherapy regimen or the other? The only demographic variable found to be significantly different was the number of children aged 16 to 19 years (see Table 13). Women in the CMF group had significantly more children in this age category than the women who chose AC. This result may have also occurred by chance due to the number of statistical tests performed. Using chi-squares and t-tests no other significant differences in demographics were found between the women who chose AC versus those who chose CMF.

Was there a significant difference between the number

of women who chose one chemotherapy regimen or the other? Sixteen women (53 percent) chose AC while 12 (40 percent) chose CMF. No significant difference was found between these frequencies. There were also no significant differences found, using the chi-square test, between the number of women who chose AC or CMF related to whether they had been presented Version One or Version Two of the decision board. However, there may be a trend towards the first option as more women chose the first treatment presented to them (see Table 12).

Summary

In summary, the results indicate that this treatment decision was not one-sided for this patient sample. Some factors were rated significantly more important than others by these women with breast cancer. Both similarities and differences were present among the responses of the women who chose AC versus those who chose CMF. Chapter Five will include the summary discussion, implications and conclusion.

CHAPTER FIVE: SUMMARY DISCUSSION IMPLICATIONS AND CONCLUSION

This study examined the decision-making process for thirty women choosing chemotherapy treatment for early stage breast cancer. The purpose was to investigate what factors were important to these patients when making a choice at this time in their lives. There was a desire to better understand what factors were considered by this patient population when invited to participate in treatment decision making. Through the use of a self-directed learning approach, women were given the opportunity to participate in an educational activity about their own health care and ultimately the process of critical thinking.

Factors Influencing Treatment Choice

A comparison within and between the factors and reasons for treatment choice reveals considerable agreement among those items considered to be the three most important. Some common themes emerge from these findings. Although the items may appear in a slightly different order, among the rankings from the whole group, the AC group, and the CMF group and between the rankings of the factors and the reasons, there is added consistency to the results.

There are similarities present among the rankings of certain factors rated as important. All the factors rated as the three most important for each group appear more than

once with the exception of the number of trips and hair loss. This is to say that there were some factors that were important to both the women who chose AC and those who chose CMF.

Side effects in general, vomiting, maintaining their home, and maintaining their normal routine were ranked within the three most important factors for both groups in making a choice of treatment. The women who chose CMF rated side effects in general and vomiting as significantly more important than the AC group; however, it appears that both factors were still important to the AC group. Maintaining their home and maintaining their normal routine were not rated significantly different, in terms of importance to the treatment choice, by the AC and CMF groups. These factors were important to everyone regardless of treatment choice.

Family role was rated as important to the whole group and to the CMF group which follows since this factor was rated significantly more important by the women who chose CMF versus those who chose AC. The ranking of the number of trips and hair loss also coincides with the statistical significance demonstrated. Therefore, there is consistency between the results from the inferential statistics and the post hoc analyses.

A similar pattern is present among the reasons given by the women for their treatment choice. Some of the same reasons for treatment choice were given by the whole sample,

the women who chose AC, and those who chose CMF. These include quality of life, time, side effects in general, vomiting, and hair loss.

Quality of life is perhaps the most interesting and revealing reason for treatment choice. It was a popular reason for treatment choice for both the women who chose AC and those who chose CMF. This finding is very curious since the differences between the two chemotherapy regimens revolve around quality of life issues such as the treatment schedule and side effects. These results support the fact that quality of life is very subjective and can only be defined by the individual based upon what she believes matters most. It is evident that there were various perspectives among the women about the meaning of the different characteristics of the chemotherapy regimens.

Time as a reason for treatment choice sparked some interesting comments from the women. All the women who chose AC gave time as a reason and all the women who chose CMF did not. Initially, one would assume this is logical for who would choose a longer treatment regimen because of time; however, a few women stated they considered choosing CMF with time as a reason because they were tempted to think six months of treatment might be better than two months in preventing disease recurrence.

Hair loss, side effects in general, and vomiting were reasons given almost exclusively by women who chose CMF.

Therefore, the ranking of these three reasons as the third most common response by the whole group is accounted for by the number of women who chose CMF and gave hair loss, side effects in general and vomiting as reasons.

Women from both treatment groups gave reasons related to concerns about family as reason for treatment choice; however, it was not one of the three most popular responses for either the AC or CMF group.

Upon comparison, agreement is also evident between the factors considered most important related to treatment choice and the reasons given most often for treatment choice. The terms "quality of life" and "time" were not listed in the factor table and therefore are not specifically presented as important factors in the results. This investigator felt that as single factors both represented concepts that were too broad for the responses to be informative. However, a connection between quality of life and time exists with several of the factors.

The quality of life category, created from the reasons stated by the women, accounts for the responses related to maintaining their normal routine and maintaining their home. Both of these as factors can be argued to be quality of life issues. Several of the reasons given by the women, regarding quality of life, referred to feeling well during treatment in order to keep up with what they would normally be doing. Examples of quality of life reasons given were

"I want to be able to get back on track" and "It is right for me and my lifestyle."

Also, the quality of life category may have accounted for the strength of importance of the side effects as factors. Although side effects in general, vomiting, and hair loss were clearly present as important factors and reasons, they appeared to be more important as factors and less important as reasons. Reasons that were allocated to the quality of life category included statements such as "I don't want to be ill from the treatment," "I want to feel good while on chemo," and "I chose CMF as it seemed less harsh." The women did not specifically state "side effects" but they alluded to them. Therefore this may account for some of the difference in the ranking of these items.

The number of trips is visible as both an important factor and reason for treatment choice. Perhaps there is some connection between time and the number of trips related to the overall number of treatment visits required and the time frame they span. If there is some connection between time and the number of trips, it could be that some of the responses for the number of trips as an important factor are somewhat divided between time and the number of trips as reasons.

Family role as a factor and family concerns as a reason are connected through a common concern for spending time with and caring for family members and fulfilling their role

as a wife, mother, daughter, or sister. Examples of the reasons given by women that were grouped into this category are "I want to have time for my kids" and "My mother is not well, I have to look after her."

It is clear that some factors and reasons for treatment choice were ranked important by only a few women. Factors common to all three groups that were rated as less important were what family might think, what friends might think, and financial concerns. Reasons given by one or two women for their treatment choice were nausea, the effect of treatment AC on the heart, work, and the influence of others.

The experience of a friend is worth noting since it was rated more important by the women who chose CMF than by those who chose AC. This makes sense because CMF is regarded as the "standard" chemotherapy treatment for premenopausal women with Stage II breast cancer and is more commonly offered by other cancer centres than AC. It is also used for women with other stages of breast cancer unlike AC. Therefore, there are many more former breast cancer patients who have had CMF chemotherapy than AC for current patients to be in contact with.

In summary, it appears that for many women the bottom line of their treatment decision was the time factor versus the side effect factor. Those who chose AC were willing to take their chances on experiencing the side effects for the sake of being finished treatment in less than half the time

it would take for CMF. Those who chose CMF were less concerned about time and more concerned about the risk of side effects. Both groups expressed quality of life as an important factor related to their chemotherapy choice.

Self-Directed Learning and The Decision Board

According to the work of Knowles (1975, 1980, 1984, 1989, 1990) and Candy (1991) the self-directed learning process was evident throughout this study in several ways.

In reviewing the basic assumptions of andragogy, it can be seen how these assumptions were followed during this learning experience. The women recognized their need to know more information about chemotherapy for breast cancer. They came to the consultation seeking more information about cancer treatment with some degree of readiness to learn.

The women were treated as independent and responsible individuals with regards to their own health care. They were invited to participate in the decision board presentation and informed from the start that they would have the opportunity to participate in choosing their own treatment. A supportive learning environment was established that emphasized respect for the individual. The learner's experience contributed to the interaction during the decision board presentation since most women openly discussed their prior knowledge of chemotherapy, the

experience of other cancer patients they knew, their employment or training, and their family situation.

The decision board was an interactive learning activity that followed an organized sequence. The practical application of the information was clear. The women, and their family and friends accompanying them, had the opportunity to ask questions to ensure personal learning needs were being met. This investigator acted as an educator and resource person in providing information and facilitating the decision-making process. The women as learners were mutually involved in planning their treatment.

It is important to note that several women came to their consultation keeping in mind traditional ideals about medical practice and education. This is understandable as the diagnosis of a life-threatening illness was unfamiliar territory for these women. This supports Knowles' (1990) point that not all learners are automatically self-directed and that the ability for this kind of learning needs to be fostered. It is questionable though whether all women preferred to be or had a deep psychological need to be self-directed.

Personal autonomy and autodidaxy, two components of self-directed learning as defined by Candy (1991), were also present during the decision board experience.

The women in this study exercised their personal autonomy to varying degrees. Personal autonomy was apparent

as the women demonstrated their freedom of choice and their independence and followed through with their chosen plan. For some women, their treatment choice was independent of the influence of others. For other women, they consulted other people to provide them with assistance. Some sought out further sources of information about chemotherapy as well as alternative treatments. The awareness of the need to interact with others to assist the decision-making process is considered autonomous thinking as much as independent decision making. All women were able to make a choice and proceeded to put that choice into action.

As Candy (1991) notes, autonomy is not simply a personal characteristic. It involves the interaction between the individual and the situation. Therefore, a person can be autonomous in some situations and not others. Situational variability helps to account for the varying level of difficulty experienced by the women in making a decision. At first, three women were resistant to the responsibility they were being given under these serious circumstances. They were surprised about the opportunity to participate in their treatment decision and had expected to be told what to do. One woman in particular expressed the most difficulty with her treatment decision and spoke of being unfamiliar with this kind of situation, participation in treatment decisions. The other women in the sample appeared to accept the active role in choosing their

treatment fairly readily yet proceeded to report varying levels of difficulty with the decision-making process. Therefore, the desire for active participation in treatment decision making does not necessarily indicate that the decision-making process will be simple. In addition, it can be argued that deciding not to choose is still exercising personal choice and autonomous thinking. However, since this was the first experience I had with these women I have no knowledge of their level of personal autonomy in other situations.

The cancer centre consultation, as all health care consultations are, is an autodidactic opportunity for it is a learning experience that takes place outside of a formal educational setting. It is interesting that the majority of patients do not recognize health care education, at a clinic appointment or during a hospital stay, as a learning experience. This supports Candy's (1991) point that most people seldom recognize autodidactic situations as learning experiences and educational opportunities.

Following autodidaxy, the decision board experience was learner-centred. Initiative and purpose were demonstrated as the women came to the consultation seeking information, then left having been given the information, perhaps sought out other resources, and returned with a decision made.

This learning experience was life-centred for these women. The decision board and decision-making experience

promoted the transition from dependency towards self-directed learning, with regards to both health care and education. This decision experience encouraged women to look within themselves, examine their own basic assumptions, and open their mind to possible treatment for a life-threatening illness, something they probably never dreamed they would have to face in the near future.

Treatment Decision Making and The Critical Thinking Process

The treatment decision-making process seen in this study follows Brookfield's model of critical thinking.

In this case the diagnosis of breast cancer was the trigger event. For these women the trigger was a negative event that was likely unexpected. The diagnosis of a life-threatening illness can cause great upset, shock, and disbelief, particularly for someone who has had good health. The extent of the impact likely varied according to the individual and her personal situation. Since the women in this study were not seen until later in the process, I am unable to comment further on their immediate reactions.

Following diagnosis, appraisal (self-examination) was the time taken by each woman to assess the meaning of this event for her and to decide how she wanted to cope with her cancer diagnosis. At this point each woman was clarifying her concerns and identifying what her goals were: for example, to fight the disease, to regain health, and to

maintain life. While trying to sort this out she may have experienced feelings of grief, anger, depression, and confusion and raised questions such as "Why is this happening to me?" She may also have sought out others who have or have had breast cancer in an attempt to identify with someone else in a similar situation. (The Canadian Cancer Society offers a volunteer visitor program for women with breast cancer called Reach to Recovery. Most women are referred to this program, soon after their diagnosis, by a health care professional.) The appraisal phase may have involved coping with decisions regarding surgical treatment and the start of considering future treatment such as radiation and chemotherapy. This phase began prior to their consultation appointment at the cancer centre. The realization of the meaning of this cancer diagnosis led each woman to the next phase.

The exploration phase included a search for ways to cope with this diagnosis such as investigating treatment alternatives. At this point women came for their consultation at the cancer centre in search of an expert opinion and treatment recommendation about the possible benefit of additional treatment following surgery. Often they came looking for an explanation or information to help them to make sense out of this situation. They were offered information and the opportunity to participate in their treatment decision. They were given the opportunity to

choose from two equally effective chemotherapy regimens based upon their ideals, beliefs and concerns. For some women this may have been a new approach to health care delivery that they had not been exposed to previously. Other aspects of the exploration phase may have included searching for other ways of coping with the social, family, and emotional components of a cancer diagnosis.

Alternative perspectives were developed following the consultation and decision board presentation. Each woman went home to think about the information, her options and the process of taking on an active role in her own care. For some women, the treatment decision took longer than for others and some claimed it was more difficult than did others. However, a decision was reached when they found a treatment option that made sense to them, that was congruent with their underlying assumptions. Each woman was able to arrive at a decision based upon what she felt was important.

Developing alternative perspectives often involves abandoning previously held beliefs. This can be very difficult. Probably everyone underwent a change in their perspective about their health from "being a healthy person" to "having a cancer and needing chemotherapy treatment." For the women in this study it was particularly distressing for those who had held beliefs such as "I don't believe in taking any medicine." "You're the experts, I don't know what I should do," or "I know someone who had chemotherapy

and they got very sick and then died." Surprisingly enough, those who did experience bothersome side effects appeared to have little difficulty accepting that the side effects made them feel worse temporarily in order to be healthier for the long-term.

The integration phase included integrating new perspectives, beliefs, and choices into their way of life. The treatment schedule meant alterations in routine for treatment visits, travelling, monitoring for side effects, and for some taking prescription tablets as part of their chemotherapy or to control side effects. The integration of new assumptions for these women also affected their routines and relationships with others such as family, friends, and those at the workplace.

Integration was also evident as some women spoke of and wrote on their questionnaire about the importance of maintaining a positive attitude for their successful recovery. Others commented on the psychological side effects of treatment and trying to mentally prepare themselves to focus all their will and energy on achieving a cancer-free outcome.

The integration phase was easier for some women than others. On subsequent clinic visits some women talked about the disruption to their lives and wanting everything to return to normal as soon as possible. Others spoke of feeling control and satisfaction with their new schedule,

not that they wanted to be in this situation but that they were dealing with it effectively.

The critical thinking process for the women in this study extends beyond their chemotherapy decision experience. It will likely continue for some time as they progress through different phases of coping, with the diagnosis of a life-threatening disease, and come to question and reevaluate their thinking, behaviour, and underlying assumptions.

Decision-Making Behaviour

A variety of decision behaviours was noted in this study that contributes to the work of Pierce (1993). As discussed in Chapter Two, Pierce identified three styles of decision-making behaviour from her study of women with breast cancer. I discovered several points of interest in considering my results in relation to Pierce's work.

The easiest style to identify was the deferrer. I found several of the women demonstrated qualities of the deferrer style as Pierce described. These women commented on their immediate attraction to what they perceived to be the safest treatment option such as "I decided in the car on the way home" and "I never even considered AC." Although most women stated they had no difficulty with their decision, two women indicated their decision had been a little bit and somewhat difficult.

The next two styles I found more difficult to identify. The highest number of women appeared to demonstrate the delayer style. However, I found I was tempted to place women in the delayer category when their behaviour did not seem to coincide with either of the other two styles. Overall, these women claimed to experience some conflict in their decision making, usually with regards to weighing the side effects versus the length of treatment. A few women referred to reading popular sources of information. Some appeared to follow the first difference rule but most seemed to consider the whole picture when choosing their treatment. The latter is unlike what Pierce found. These women rated their decision from having been a little difficult to very difficult.

The women who exhibited the deliberator style appeared to demonstrate only one or two qualities of this style. I primarily identified this style in the women who had informed me about their information search and those who rated their decision as having been difficult. Of the five women I found displaying this style, three said they had searched for more information or had sought other opinions such as their family physician or a specialist in naturopathic therapies. These three women also rated their decision as quite or very difficult. Another woman planned and performed a strategic information search about conventional treatment and made her choice with great

confidence. She expressed a personal responsibility for making the right choice and then rated her decision as not difficult at all. Confidence with choice and a lack of difficulty with the decision is unlike what Pierce described for the deliberator style. With the exception of this woman in particular, I am uncertain about whether the issue of having control was important to these women.

Overall two women, a delayer and deliberator, directly stated they were unfamiliar with this form of health care practice and were somewhat confused as to how they could begin to make a choice. They said they felt less than qualified to participate in their treatment decisions. The woman, whom I identified as a deliberator, saw her family physician to assist her with her choice and rated her decision as quite difficult. The other woman, whom I identified as a delayer, referred to popular information rather than professional opinion and rated her decision as very difficult.

Overall, the women I saw as deliberators did not consistently rate their decision as having been very difficult; as well as, not everyone who stated their decision was difficult performed the elaborate information search Pierce described.

Another interesting observation was that two women did not follow through with their treatment plan. One woman, whom I identified as a deliberator, stopped taking CMF after

one month of treatment. She had rated her decision as having been quite difficult and was rather reluctant at the time to make a choice at all. This follows the deliberator style as Pierce described that these individuals are often less satisfied with their decision and anticipate regretting their decision in the future.

Another woman, whom I identified as a deferrer, changed her mind after one month of treatment and asked to switch treatments from CMF to AC. The main reason for her choosing CMF had been to reduce her chance of hair loss while on treatment. After one cycle of CMF she lost her hair. This woman had been attracted to CMF since there was a lesser chance of hair loss and as soon as that attractive feature was no longer present she desired the other treatment. When hair conservation was no longer a feature of CMF she was attracted to AC for the shorter treatment schedule. With the exception of these two, most women expressed some degree of confidence with their decision making and were satisfied with their choice.

For all three styles of decision making the percentage of women who exhibited each one was similar to the proportions Pierce found. For example, the smallest group of women demonstrated the deliberator style. All three styles of decision-making behaviour were demonstrated by women from both treatment choice groups.

Safety and risk were considered by all women. Their consideration of safety was more evident through their treatment choice than their decision-making behaviour. Generally, those women who chose CMF were more averse to risk towards the side effects than those who chose AC. I was unable to establish the decision-making style of the delayers and deliberators based upon their consideration of risk.

It is entirely possible that behaviours characteristic of each style may have been demonstrated by the women without my knowledge. This may have either added to the strength of my classification of their styles or changed some of the classifications completely. Also, as a group these women displayed a wide range of emotions. This was expected as individuals were in different phases of coping with their diagnosis. Perhaps the possible link between emotional coping and decision-making behaviour needs to be addressed. Pierce's work adds insight into the decision-making process for women with breast cancer; however, there is a need for further research in this area.

Implications for Theory

Overall the findings from this study are congruent with the theoretical framework used. The results support the link between critical thinking and decision making in health care, particularly for breast cancer patients involved in

making treatment choices. However, the results also demonstrate that not every woman preferred to be self-directed in her learning. This somewhat contradicts one of Knowles' basic assumptions which states that everyone prefers and has a deep psychological need to be self-directed. This assumption has been challenged by Brookfield (1986) among others. Results of this study support the need to question the notion of universal self-directed learning. Perhaps especially in a difficult emotional context, self-directed learning is not appropriate for all individuals.

Implications for Research

The results from this study have led to the formulation of more research questions. Since quality of life was a major factor in this treatment decision for this group of women, further assessment of quality of life variables would be useful. A plan to follow the quality of life of the women in this study is already in place. Also related to quality of life is satisfaction with choice. This would be an important concept to measure during and after treatment completion. This feedback may reveal information that women feel they should be aware of when making their choice.

The assessment of learning retention from the decision board later on in the treatment process would be another area to explore. This could provide more evidence about the effectiveness of the decision board as an educational tool

or the need for formal reinforcement of learning for patients throughout their treatment course.

Longitudinal research in this area with regards to both quality of life and learning would be helpful to answer these questions.

Subject recruitment and data collection for this study are being extended. As more information is obtained, it will be important to further note the effect of order of presentation on treatment choice.

Qualitative research in this area would be important. Analysis of interviews and discussion could reveal more information about the decision-making experience for patients offered the opportunity to participate in their treatment decisions. Information about what people or agencies are often contacted, for support, during the decision time as well as spouse and family reaction and involvement in the decision-making process would be beneficial knowledge.

Future research must acknowledge the differing levels of participation desired by patients. Although previous research supported the active involvement of young females with breast cancer in the treatment decision-making process, this study provided evidence that not every woman wanted that responsibility. The level of difficulty with treatment decisions is also important to continue to measure to learn

more about those in particular who have difficulty with their decision-making process.

Overall, the literature demonstrates that there is a need to further explore the factors which are important to breast cancer patients when involved in treatment decisions, particularly about chemotherapy. It would also be interesting to investigate the same research questions with other cancer patient populations.

Implications for Practice

The results from this study may have an impact on practice. Further knowledge about the decision-making process for women with breast cancer has provided the nurses and physicians of the clinic with greater insight into why women make the choices they do. Quality of life has been revealed as a primary factor related to treatment choice that can only be defined by the woman herself. The need to develop a mechanism to help facilitate the process of critical thinking and assist those having difficulty making a decision is also recognized.

This decision board is the third of its kind as an instrument to encourage participation in treatment decisions for women with breast cancer. Hopefully this research has added to its merit as an educational tool for patient education in a busy clinic setting. The results show that patients can understand and learn information related to

their health conveyed in this manner, and that they found the decision board helpful for decision making.

As an extension of this study the quality of life of these thirty women has been followed throughout their treatment and for a few months afterward. These data, which are still being collected, may later suggest important similarities and differences between the two groups, providing us with additional information.

The results obtained from this study could be useful to all health care professionals involved in the care of women with breast cancer. The staff of the breast clinic at the Hamilton Regional Cancer Centre have continued to offer women with Stage II breast cancer this choice using the decision board and plans have been made to formally continue patient recruitment and data collection.

The results from this study will be presented at a poster session at the 17th Annual San Antonio Breast Cancer Symposium in December, 1994.

Conclusion

There is a general movement throughout health care toward increased patient involvement in decision making regarding care. This trend follows those from the adult education frameworks of self-directed learning and critical thinking.

When a person is in a context where she is dealing with an important personal decision while under the duress of serious illness, what is that decision-making process like? This study investigated what factors were most important to women newly diagnosed with breast cancer when choosing between two equally effective chemotherapy treatments. The women in this study considered quality of life as a major factor in their decision-making process.

In fact, the whole issue that the women were dealing with is one of quality of life: for example, illness versus health. They identified the side effects and time as important factors related to their decision which really are properties of quality of life in this situation. So how can we encourage autonomy, self-directed learning, and critical thinking in a way that also enhances quality of life?

As self-directed learning and critical thinking promote personal empowerment which in turn helps to encourage quality of life, it can be said that quality of life is what adult education is all about. This study supports that philosophy.

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Appendix A

Decision Board - Version One

Chemotherapy

Chemotherapy kills cancer cells. It circulates throughout your body in the blood stream.

Along with cancer cells chemotherapy sometimes kills normal cells such as blood cells, the cells lining your mouth and digestive tract and hair cells.

This can cause low blood counts, less resistance to infection, feeling tired, mouth sores, diarrhea and hair loss. Normal cells will grow back.

Chemotherapy improves your chance of survival. It reduces the risk of the cancer coming back. However even with chemotherapy there is a chance the cancer may return.

Treatment A and Treatment B provide the same protection against the cancer coming back.

Treatment Choice

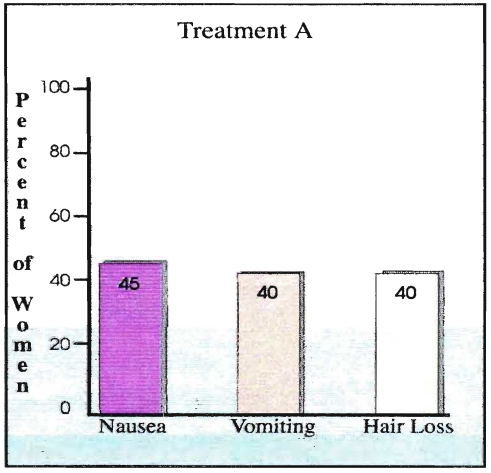
Treatment A - CMF

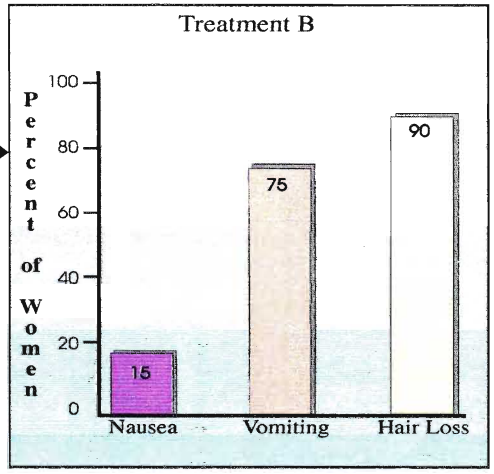
- Treatment lasts 6 months.
- 3 Drugs (2 by I.V. and 1 by mouth).
- Two visits per month to get I.V. drugs.
- Takes about 20 minutes for nurse to give I.V. drugs.
- Take pills for 2 weeks of every month.
- 12 Clinic Visits.

Treatment B - AC

- Treatment lasts 2 1/2 months.
- 2 Drugs (both by I.V.).
- One visit every 3 weeks to receive drugs.
- Takes about 60 minutes for nurse to give I.V. drugs.
- 4 Clinic Visits.

Side-Effects





Appendix B

Stage II Breast Cancer Treatment Questionnaire A

STAGE II BREAST CANCER TREATMENT QUESTIONNAIRE A

NAME: _____ DATE: _____

SECTION #1

Please answer the following questions about your lifestyle.

1. Your present age: _____ Years

2. Your present marital status. (Circle number)

   1 Never married
   2 Married
   3 Separated
   4 Divorced
   5 Widowed

3. Number of children you have in each age group. (If none, write "0")

   NUMBER OF CHILDREN

   _____ Under 5 years of age
   _____ 5 to 10
   _____ 11 to 15
   _____ 16 to 19
   _____ 20 to 24
   _____ 25 and over

4. Will you have help during your treatment from family or friends to care for your children?

   1 Yes, all or most of the time
   2 Some of the time
   3 No, not at all
   4 Not applicable

5. Are you presently? (Circle number)

   1 Employed
   2 Unemployed
   3 Student
   4 Full-time homemaker
   5 Retired

6. What are you trained as or what is your job title/position?

   _____

7. What was your family income (before taxes) in 1992? (Circle number)

   1 0 - $10,000
   2 10,000 - 30,000
   3 30,000 - 50,000
   4 Greater than 50,000

8. What is the highest level of education you have completed? (Circle number)

   1 University
   2 College
   3 High School
   4 Other _____

9. What is your religious faith? (Circle number)

   1 Jewish
   2 Protestant
   3 Roman Catholic
   4 None
   5 Other: _____

10. Which statement best describes your religious involvement? (Circle number)

    1 I attend services weekly (or more often) and I am involved with my religious community and functions
    2 I attend services weekly
    3 I attend services occasionally
    4 I do not attend religious services

SECTION #2

Please answer the following questions about the information presented to you. It will help us to improve the Decision Board.

11. Chemotherapy can kill cancer cells and normal cells in the body.

    1 Yes
    2 Unsure
    3 No

12. Normal cells can recover from chemotherapy and grow again.

    1 Yes
    2 Unsure
    3 No

13. Treatment A and Treatment B offer the same chance of survival, they both help prevent the cancer from coming back.

    1 Yes
    2 Unsure
    3 No

14. Treatment B - AC takes 4 months to finish.

    1 Yes
    2 Unsure
    3 No

15. Treatment A - CMF means coming to the centre 12 times for treatment.

    1 Yes
    2 Unsure
    3 No

16. Treatment B - AC means getting chemotherapy through an intravenous and by taking pills.

    1 Yes
    2 Unsure
    3 No

17. There is a greater chance of vomiting with Treatment A - CMF.

    1 Yes
    2 Unsure
    3 No

18. There is a greater chance of losing my hair with Treatment B - AC.

    1 Yes
    2 Unsure
    3 No

19. Did you find the Decision Board helpful?

    1 Very much
    2 Quite a bit
    3 Somewhat
    4 A little bit
    5 Not at all

Comments: _____
_____

SECTION #3

Please answer the following questions about how you made your decision. It is important for us to learn what things mean the most to patients when considering chemotherapy treatment.

20. What treatment did you choose? (Circle number)

    1 Treatment A - CMF
    2 Treatment B - AC
    3 No Treatment

21. Was it difficult for you to make this decision?

    1 Very much
    2 Quite a bit
    3 Somewhat
    4 A little bit
    5 Not at all

    Comments: _____
    _____

22. What were your 3 most important reasons for choosing the treatment you did?

    1 _____
    _____

    2 _____
    _____

    3 _____
    _____

23. Was your decision influenced by anyone? (Circle number)

    1 A doctor at the Cancer Centre
    2 A nurse at the Cancer Centre
    3 Another patient
    4 A family member or friend
    5 Other: _____

24. For the following please show the importance of each factor to your decision about chemotherapy treatment?

	VERY IMPORTANT	IMPORTANT	NOT IMPORTANT	NOT APPLICABLE
The side effects in general				
Nausea				
Vomiting				
Hair Loss				
The number of needle pokes for bloodwork & treatment				
The number of trips to the Cancer Centre				
Caring for your family (Your role as a wife, mother, daughter, sister)				
Maintaining your home (Your responsibilities alone or as part of a family-eg. housework, meals, gardening)				
The age of your children				
What your family might think				
What your friends might think				
The experience of a friend				
Returning to work				
Financial concerns (Loss of income, child care, travel expenses)				
Maintaining your normal routine				
Other _____ _____ _____				

25. What would you choose if the chance of hair loss was the same for both treatments?

1 Treatment A - CMF
2 Treatment B - AC

26. What would you choose if the chance of vomiting was the same for both treatments?

1 Treatment A - CMF
2 Treatment B - AC

27. What would you choose if both treatments took 6 months to finish?

    1 Treatment A - CMF
    2 Treatment B - AC

28. What would you choose if Treatment A - CMF meant 1 visit every 4 weeks (instead of 2 visits) to the cancer centre for 6 months?

    1 Treatment A - CMF
    2 Treatment B - AC

SECTION #4

Below is a list of statements that other people with your illness have said are important. By filling in one circle per line, please indicate how true each statement has been for you during the past 7 days.

During the past 7 days: **PHYSICAL WELL-BEING**	not at all	a little bit	some-what	quite a bit	very much
1. I have a lack of energy	⓪	①	②	③	④
2. I have nausea	⓪	①	②	③	④
3. I have trouble meeting the needs of my family	⓪	①	②	③	④
4. I have pain	⓪	①	②	③	④
5. I am bothered by side effects of treatment	⓪	①	②	③	④
6. In general, I feel sick	⓪	①	②	③	④
7. I am forced to spend time in bed	⓪	①	②	③	④

8. How much does your PHYSICAL WELL-BEING affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

During the past 7 days: **SOCIAL/FAMILY WELL-BEING**	not at all	a little bit	some-what	quite a bit	very much
9. I feel distant from my friends	⓪	①	②	③	④
10. I get emotional support from my family	⓪	①	②	③	④
11. I get support from my friends and neighbors	⓪	①	②	③	④
12. My family has accepted my illness	⓪	①	②	③	④
13. Family communication about my illness is poor	⓪	①	②	③	④
If you have a spouse/partner, or are sexually active, please answer # 14-15. Otherwise, go to # 16.					
14. I feel close to my partner (or main support)	⓪	①	②	③	④
15. I am satisfied with my sex life	⓪	①	②	③	④

16. How much does your SOCIAL/FAMILY WELL-BEING affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

During the past 7 days: **RELATIONSHIP WITH DOCTOR**	not at all	a little bit	some-what	quite a bit	very much
17. I have confidence in my doctor(s)	⓪	①	②	③	④
18. My doctor is available to answer my questions	⓪	①	②	③	④

19. How much does your RELATIONSHIP WITH THE DOCTOR affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

During the past 7 days: **EMOTIONAL WELL-BEING**	not at all	a little bit	some-what	quite a bit	very much
20. I feel sad	⓪	①	②	③	④
21. I am proud of how I'm coping with my illness	⓪	①	②	③	④
22. I am losing hope in the fight against my illness	⓪	①	②	③	④
23. I feel nervous	⓪	①	②	③	④
24. I worry about dying	⓪	①	②	③	④

25. How much does your EMOTIONAL WELL-BEING affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

During the past 7 days: **FUNCTIONAL WELL-BEING**	not at all	a little bit	some-what	quite a bit	very much
26. I am able to work (include work in home)	⓪	①	②	③	④
27. My work (include work in home) is fulfilling	⓪	①	②	③	④
28. I am able to enjoy life "in the moment"	⓪	①	②	③	④
29. I have accepted my illness	⓪	①	②	③	④
30. I am sleeping well	⓪	①	②	③	④
31. I am enjoying my usual leisure pursuits	⓪	①	②	③	④
32. I am content with the quality of my life right now	⓪	①	②	③	④

33. How much does your FUNCTIONAL WELL-BEING affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

During the past 7 days: **ADDITIONAL CONCERNS**	not at all	a little bit	some-what	quite a bit	very much
34. I have been short of breath	⓪	①	②	③	④
35. I am self-conscious about the way I dress	⓪	①	②	③	④
36. My arms are swollen or tender	⓪	①	②	③	④
37. I feel sexually attractive	⓪	①	②	③	④
38. I have been bothered by hair loss	⓪	①	②	③	④
39. I worry about the risk of cancer in other family members	⓪	①	②	③	④
40. I worry about the effect of stress on my illness	⓪	①	②	③	④
41. I am bothered by a change in weight	⓪	①	②	③	④
42. I am able to feel like a woman	⓪	①	②	③	④

43. How much do these ADDITIONAL CONCERNS affect your quality of life?

Not at all ⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Very much so

Appendix C

Chemotherapy Information for Women with Stage II Breast Cancer

Decision Board Script A

CHEMOTHERAPY INFORMATION FOR WOMEN WITH STAGE II BREAST CANCER

DECISION BOARD SCRIPT A

Dr. _____ has recommended chemotherapy treatment to you. Chemotherapy is the word for a large group of cancer-fighting drugs. This means that there are many different drugs that are called chemotherapy. These drugs are used to treat different forms of cancer in the body. The chemotherapy I am going to tell you about is used to treat this stage of breast cancer.

Chemotherapy kills cancer cells. It circulates throughout your body in the bloodstream. Along with cancer cells chemotherapy sometimes kills normal cells such as blood cells, the cells lining your mouth and digestive tract and hair cells. This can cause low blood counts, feeling tired, the risk of infection, mouth sores, diarrhea, and hair loss. The normal cells will grow back. Because of the risk of low blood counts, before each chemotherapy treatment every patient goes to the lab for a blood test and is seen by a nurse and/or doctor in the clinic.

Chemotherapy improves your chance of survival. It reduces the risk of the cancer coming back. However, even with chemotherapy there is a chance the cancer may return at some point.

Here at this centre, we offer two different chemotherapies to treat women, like yourself, who have had surgery for breast cancer (where the cancer was found both in your breast and under your arm in the lymph nodes). Both chemotherapies have the same effect, that is one is not better than the other. They both work to prevent the cancer from coming back.

Let's start with Treatment A (CMF). This treatment takes about 6 months to finish. Treatment A (CMF) is made up of 3 drugs, 2 of the drugs are given through an intravenous (IV) in your arm and 1 is a pill that you take by mouth. This treatment means 2 visits per month to the Cancer Centre to get the IV drugs. Once the drugs are prepared it takes about 20 minutes for a nurse to give the IV drugs. The pills you take for 2 weeks of each month. You will take the pills once a day, every day during the 2 weeks. This treatment means 12 trips to the Cancer Centre.

Treatment A (CMF) is made up of 6 cycles, each one lasting 4 weeks. This is how the schedule for a cycle works. On the first day you will come to the Centre and receive the 2 drugs through an IV. On that same day you will be given a prescription for the pills. You will start taking the pills the next day. One week from the first day you will come to the Centre again to receive the 2 drugs through an IV. At that time you will still have one week left of taking your pills. After this day you will return to the clinic in 3 weeks. When you finish your pills, at home, you will have 2 weeks of no chemotherapy. The cycle then repeats itself.

The side effects you may have with Treatment A (CMF) are:

1. Nausea (upset stomach) - There is a 45% chance this may happen. This is usually mild and may last for only a day or two, or most of the 2 weeks when you are taking the pills. You will be given a prescription for some medication to help this.
2. Vomiting (throwing up) - There is a 40% chance this may happen within the first 1 to 2 days after the IV chemo. You will be given a prescription for some medication to help prevent this.
3. Hair loss - There is a 40% chance you will lose half your hair or more. More often this is seen as thinning of the hair. It will grow back when you are finished chemotherapy.

Now let's talk about Treatment B (AC). This treatment takes about 2 1/2 months to finish. Treatment B (AC) is made up of 2 drugs, both are given through an intravenous (IV) in your arm. This treatment means 1 visit every 3 weeks to the Cancer Centre to receive the IV drugs. Once the drugs are prepared it takes about 60 minutes for a nurse to give the IV drugs. This treatment means 4 trips to the Cancer Centre.

Treatment B (AC) is made up of 4 cycles, each one lasting 3 weeks. Each cycle is 1 treatment of the IV drugs. On the first day of your treatment you will come to the Centre and receive the 2 drugs through an IV. Three weeks from this day you will return to the Centre for another treatment. This cycle repeats itself for a total of 4 IV treatments.

The side effects you may have with Treatment B (AC) are:

1. Nausea (upset stomach) - There is a 15% chance this may happen within a few days after chemo. You will be given a prescription for some medication to help this.
2. Vomiting (throwing up) - There is a 75% chance this may happen within the first 1 to 2 days after chemo. You will be given a prescription for some medication to help prevent this.
3. Hair loss - There is a 90% chance you will lose half your hair or more. It will grow back when you are finished chemotherapy. I can give you some information if you are interested in a wig.

These are the most common side effects of these 2 chemotherapies; however, there are others that are less common that we have not discussed.

Treatment A (CMF) can also cause irritated or watery eyes.

Both Treatment A (CMF) and Treatment B (AC) can cause bladder irritation such as burning on urination. Drinking lots of fluids after treatment will help prevent this.

After each treatment of Treatment B (AC) your urine may be red in colour because of the colour of one of the drugs. This is normal and will disappear after you have urinated a few times.

There is also a small risk of heart damage with certain doses of Treatment B (AC). When this drug has been used for a long period of time heart damage has occurred in a small number of patients. The total dose you will be given is well within the safe accepted range. As well, all the drug doses you will be given will be calculated based upon your own height and weight.

Lastly, both chemotherapies can cause changes in your menstrual cycle. The length of your cycle may change and you may even stop having your period. This may be temporary while you are on chemotherapy or it may be permanent.

If you have any questions between now and the time you return you may call me.

Ellen Irwin RN 387-9495 x-4409

Appendix D

Correlations of Factors

Correlations of Factors

Factors	Side Effects	Nausea	Vomiting	Hair Loss	# of Needles	# of Trips	Family Role	Home	Age of Children	Family Think	Friends Think	Exp. of Friend	Work	Finances	Routine	Other
Side Effects	1.00															
Nausea	.61**	1.00														
Vomiting	.79**	.85**	1.00													
Hair Loss	.65**	.72**	.69**	1.00												
# of Needles	.05	.16	.10	.15	1.00											
# of Trips	-.18	-.11	-.20	.03	.54*	1.00										
Family Role	.06	-.05	.03	-.09	-.39	-.48*	1.00									
Home	-.04	-.08	.00	-.06	-.28	-.37	.75**	1.00								
Age of Children	.05	-.14	.03	-.19	-.21	-.20	.51*	.30	1.00							
Family Think	-.03	-.04	-.03	.11	-.01	.06	.39	.47*	.41	1.00						
Friends Think	-.05	.18	.01	.13	.13	.23	.19	.26	.10	.76**	1.00					
Exp. of Friend	.31	.23	.32	.28	.02	-.12	.41	.49*	.19	.33	.36	1.00				
Work	-.10	-.04	-.05	.02	.42	.21	-.29	-.06	-.29	.02	-.04	.36	1.00			
Finances	.05	.07	.03	.06	.18	.15	-.08	-.14	-.18	-.01	.10	.32	.63**	1.00		
Routine	-.30	-.05	-.14	-.02	.03	-.07	.20	.18	.28	.18	.01	.32	.41	.34	1.00	
Other	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	1.00

* $p < .01$ ** $p < .001$

Appendix E

Correlations of Quality of Life

Correlations of Quality of Life

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q17	Q18	Q20	Q21
Q1	1.00																	
Q2	.24	1.00																
Q3	.38	.22	1.00															
Q4	.17	.60**	.55*	1.00														
Q5	.14	.13	.31	.58*	1.00													
Q6	.49*	.70**	.33	.49*	.31	1.00												
Q7	.31	.53*	.42	.75**	.60**	.77**	1.00											
Q9	-.23	-.12	-.21	-.04	-.01	.07	.06	1.00										
Q10	-.02	.16	.18	.20	.28	.16	.22	-.16	1.00									
Q11	-.09	.11	.10	.05	.05	-.21	-.15	-.63**	.43	1.00								
Q12	-.11	.09	.12	.02	.24	.10	.16	-.18	.50*	.59**	1.00							
Q13	-.27	.19	.51*	.58*	.16	.31	.46	.47	-.07	-.33	-.11	1.00						
Q14	-.38	-.04	-.51*	-.09	.23	-.17	-.03	.05	.08	.10	.30	-.39	1.00					
Q15	-.17	-.06	-.60*	-.33	.03	-.18	-.35	.27	-.15	-.12	.00	-.41	.53*	1.00				
Q17	-.32	-.19	-.43	-.36	-.23	-.58*	-.66**	.17	.00	.02	-.16	-.19	.13	.33	1.00			
Q18	-.08	-.08	-.04	-.10	-.24	-.09	-.08	-.27	.34	.04	.00	-.08	-.11	-.18	.03	1.00		
Q20	.46	.44	.45	.39	.22	.46	.30	.11	.00	-.11	-.30	.17	-.29	-.09	-.39	-.18	1.00	
Q21	-.23	-.40	-.35	-.23	.21	-.56*	-.28	-.06	-.07	.11	.12	-.35	.44	.39	.32	-.01	-.45	1.00
Q22	-.10	.56*	.05	.23	-.25	.27	.11	-.19	.21	.23	.11	.17	-.05	-.34	-.04	.13	.31	-.40
Q23	.04	-.22	-.17	-.20	-.29	-.21	-.17	.18	-.11	-.37	-.48	-.05	-.22	-.10	.30	.22	.08	.08
Q24	.06	.26	-.17	.03	-.32	.16	-.08	.29	.18	-.09	-.10	-.01	-.40	-.01	.15	.12	.28	-.39
Q26	-.57*	-.11	-.55*	-.19	-.12	-.22	-.07	.35	-.07	-.13	.07	.13	.46	.35	.47	.04	-.64**	.24
Q27	-.28	-.37	-.39	-.24	-.07	-.35	-.18	.33	-.33	-.38	-.26	.01	-.02	.30	.57*	-.06	-.51*	.31
Q28	-.51*	-.50*	-.55*	-.34	-.09	-.55*	-.32	.13	-.11	.04	.08	-.03	.47	.26	.35	.05	-.58*	.54*
Q29	-.11	-.15	-.14	-.16	-.05	-.27	-.17	-.24	-.20	.30	.49*	-.06	.38	.13	-.10	.06	-.36	.54*
Q30	-.15	-.30	-.18	-.46	-.34	-.10	-.10	-.02	-.18	-.13	-.02	-.05	-.01	-.02	.11	-.05	-.45	.12
Q31	-.24	-.16	-.50*	-.32	-.15	-.29	-.22	.21	-.16	-.10	.16	-.20	.35	.30	.44	.00	-.46	.45
Q32	-.29	-.35	-.38	-.48*	-.23	-.38	-.25	.24	-.28	-.22	.09	-.22	.54*	.35	.16	.00	-.49*	.37
Q34	.34	.24	.27	.39	.55*	.40	.46	-.06	.07	-.01	-.05	-.18	.15	.10	-.59**	-.24	.53*	-.11
Q35	.21	.15	.21	.11	.19	.15	.12	.31	.19	-.08	.01	-.03	-.26	.20	.15	.05	.40	-.05
Q36	.10	.44	.28	.34	.13	.35	.30	.29	.19	-.26	-.16	.33	-.27	-.03	.00	.13	.44	-.08
Q37	-.08	.17	-.18	-.14	.16	.04	-.01	-.28	.25	.28	.37	-.44	.29	.19	.28	.13	-.33	.30
Q38	-.13	-.07	.16	.24	.49*	.11	.24	.56*	.20	-.34	.05	.37	.02	.13	.14	-.02	.15	.19
Q39	.19	-.07	-.01	-.07	.05	.02	-.05	.25	.14	-.34	-.38	-.07	-.25	.17	.19	.17	.20	-.13
Q40	.08	.33	.20	.36	-.03	.13	.25	.02	.18	-.25	-.29	.19	-.18	-.02	.15	.34	.17	-.01
Q41	.16	.62**	.27	.35	-.04	.39	.21	.11	.12	-.04	-.11	.31	-.54*	-.13	.01	.12	.53*	-.31
Q42	-.26	-.09	.15	.05	.16	-.08	.05	-.36	.42	.41	.60**	-.04	.26	-.22	-.18	.28	-.52*	.26

Continued ...

Correlations of Quality of Life Continued

	Q22	Q23	Q24	Q26	Q27	Q28	Q29	Q30	Q31	Q32	Q34	Q35	Q36	Q37	Q38	Q39	Q40	Q41	Q42
Q1																			
Q2																			
Q3																			
Q4																			
Q5																			
Q6																			
Q7																			
Q9																			
Q10																			
Q11																			
Q12																			
Q13																			
Q14																			
Q15																			
Q17																			
Q18																			
Q20																			
Q21																			
Q22	1.00																		
Q23	.02	1.00																	
Q24	.25	.38	1.00																
Q26	-.14	.04	-.06	1.00															
Q27	-.45	.39	.10	.69**	1.00														
Q28	-.06	.03	-.29	.62**	.37	1.00													
Q29	-.19	-.25	-.43	.34	.08	.48	1.00												
Q30	-.01	.04	-.23	.32	.27	.45	.05	1.00											
Q31	-.10	.18	.04	.57*	.46	.59**	.41	.20	1.00										
Q32	-.29	.07	-.12	.56*	.42	.38	.38	.34	.50*	1.00									
Q34	-.14	-.20	-.06	-.40	-.42	-.49*	-.21	-.35	-.50*	-.08	1.00								
Q35	-.06	.21	.28	-.18	.12	-.22	-.40	-.22	.08	-.20	-.02	1.00							
Q36	.32	.09	.15	-.31	-.19	-.29	-.37	-.26	-.15	-.44	-.05	.65**	1.00						
Q37	.06	-.18	-.23	.23	.11	.04	.03	.16	.33	.16	.02	.09	-.05	1.00					
Q38	-.20	.16	.00	.06	.19	.10	-.15	-.31	.18	-.15	-.05	.59**	.51*	.02	1.00				
Q39	-.03	.20	.16	-.03	.28	.01	-.47	.08	-.19	-.10	.11	.39	.25	.04	.23	1.00			
Q40	.19	.41	.33	.04	.15	-.22	-.20	-.18	.01	.02	-.01	.28	.41	-.06	.18	.19	1.00		
Q41	.45	.12	.43	-.27	-.14	-.40	-.25	-.38	-.19	-.55*	-.12	.51*	.74**	-.13	.30	.24	.41	1.00	
Q42	-.12	-.10	-.22	.13	-.09	.01	.41	-.04	.00	.11	.04	-.34	-.32	.34	-.04	-.39	-.15	-.29	1.00

*p < .01 **p < .001

Appendix F

Decision Board - Version Two

Chemotherapy

Chemotherapy kills cancer cells. It circulates throughout your body in the blood stream.

Along with cancer cells chemotherapy sometimes kills normal cells such as blood cells, the cells lining your mouth and digestive tract and hair cells.

This can cause low blood counts, less resistance to infection, feeling tired, mouth sores, diarrhea and hair loss. Normal cells will grow back.

Chemotherapy improves your chance of survival. It reduces the risk of the cancer coming back. However even with chemotherapy there is a chance the cancer may return.

Treatment A and Treatment B provide the same protection against the cancer coming back.

Treatment Choice

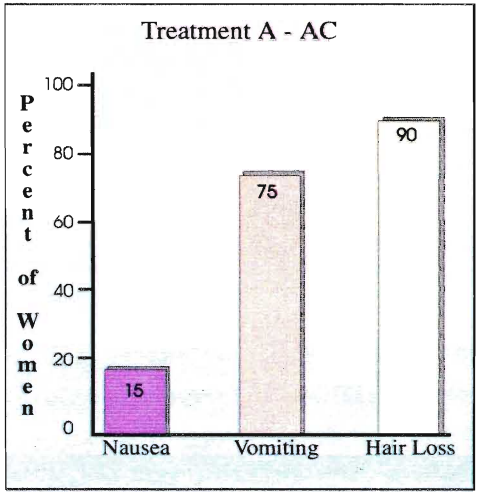
Treatment A - AC

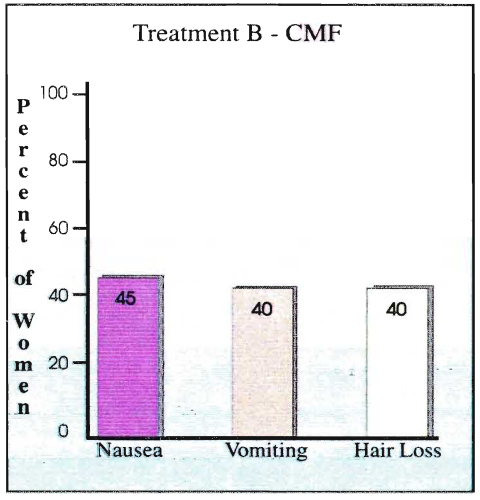
- Treatment lasts 2 1/2 months.
- 2 Drugs (both by I.V.).
- One visit every 3 weeks to receive drugs.
- Takes about 60 minutes for nurse to give I.V. drugs.
- 4 Clinic Visits.

Treatment B - CMF

- Treatment lasts 6 months.
- 3 Drugs (2 by I.V. and 1 by mouth).
- Two visits per month to get I.V. drugs.
- Takes about 20 minutes for nurse to give I.V. drugs.
- Take pills for 2 weeks of every month.
- 12 Clinic Visits.

Side-Effects





Appendix G

Hamilton Regional Cancer Centre

Consent Form

Hamilton Regional Cancer Centre
699 CONCESSION STREET, HAMILTON, ONTARIO L8V 5C2 • TEL: (416) 387-9495
Centre Régional de Cancérologie de Hamilton

CONSENT FORM

FACTORS AFFECTING TREATMENT DECISION MAKING
FOR WOMEN WITH BREAST CANCER

I understand that I have been asked, with the approval of my physician, to participate in a research study looking at the use of a Decision Board (a teaching tool) to explain the differences between the two chemotherapy regimens (CMF & AC) used to treat Stage II Breast Cancer in premenopausal women; as well as, what factors are most important to women in this situation when making a decision about their treatment.

My role in this study will be to listen to the Decision Board presentation and complete some questionnaires. The Decision Board will be presented to me today. I will be asked to complete the questionnaires when I return to the Cancer Centre for other visits. I understand my questionnaires will be kept confidential and will be used for research purposes only.

I agree to participate in this study and understand the information stated above.

_____ _____
Signature of Participant Date

_____
Signature of Witness

_____
Signature of Investigator